

Health Locus of Control and Assimilation of Cervical Cancer Information in Deaf Women

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Abstract This study assessed the relationship between Deaf women's internal health locus of control (IHLC) and their cervical cancer knowledge acquisition and retention. A blind, randomized trial evaluated Deaf women's ($N=130$) baseline cancer knowledge and knowledge gained and retained from an educational intervention, in relation to their IHLC. The Multidimensional Health Locus of Control scales measured baseline IHLC, and a cervical cancer knowledge survey evaluated baseline to post-intervention knowledge change. Women's IHLC did not significantly predict greater cervical cancer knowledge at baseline or

over time. IHLC does not appear to be a characteristic that must be considered when creating Deaf women's cancer education programs.

Keywords Multidimensional Health Locus of Control (MHLC) · American Sign Language (ASL) · Deaf · Cervical cancer · Education

Introduction

Cervical cancer is an increasingly controllable disease through prevention (sexual abstinence and human papillomavirus (HPV) vaccination), early detection (adherence to recommended screening guidelines for Pap tests), and prompt, appropriate treatment [1–4]. Thus, women's access to and use of cervical cancer knowledge and services are vital to their survival [5]. Deaf women are among the minority groups that have been shown to experience barriers to accessing health information and services due to language and cultural barriers [6]. This paper explores the relationship between Deaf women's internal health locus of control (IHLC) and their possession, acquisition, and retention of cervical cancer knowledge.

Background on the Deaf Community

The Deaf community experiences many of the same language and cultural barriers to accessing health information and care as do other minority communities [7, 8]. The word Deaf with a capital “D” is used to signify those people who share a common language (American Sign Language (ASL)) and culture (Deaf culture), as opposed to a lower case “d” which is an audiological term. Within this community, English literacy levels average between fourth

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and fifth grade because English is learned as a second language, if it is learned at all [9–11]. Members of the Deaf community possess varying levels of ASL, lip reading, and note writing skills and combine their skills to achieve optimum communication.

Compounding this literacy barrier is the severe shortage [12] of healthcare professionals and public health educators who are proficient in ASL [8, 13, 14]. This makes the mainstream health education strategies less effective for the Deaf community than for the general public and can lead to misconstrued health information among Deaf individuals [15–18]. The communication barriers experienced by Deaf women are compounded by cultural differences [8, 13, 15, 18–20] and mistrust of the medical system that further deter Deaf women from accessing vital health services [7, 13, 14, 16, 17, 21, 22]. These factors place Deaf women at greater risk for receiving medical care late for preventable or treatable illnesses and consequently, increase their odds of greater morbidity, sequelae, and mortality rates [13].

Internal Health Locus of Control

It has long been established that people’s perceived ability to control their health influences their efforts to accumulate and use health knowledge [23]. Social learning theory predicts that people will participate in goal-directed behavior if they value the goal and believe that their actions will help them achieve that goal [24, 25]. Thus, a woman would be expected to seek information about a health-threatening illness if she values her health and believes that changing her behavior will lead to better health [26]. People with a strong IHLC believe that their behaviors determine their health status. They are more likely to seek information about health-threatening conditions and engage in healthier behaviors, such as disease prevention, to maintain their health [23, 27, 28]. Women with high IHLC, i.e., who believe that they control their own health, have been shown to be more likely to engage in cervical cancer screening [29, 30].

Cervical Cancer Education for Deaf Women

Prior research has shown that minority women and women with disabilities are less likely to receive a Pap smear within the last 12 months or to have continuity in their medical care [3, 17, 31]. A new cervical cancer education video (Cervical Cancer: Catch It Early and Save Your Life) was specifically developed to help Deaf women reduce their risk of discovering their cervical cancer at later stages by improving their access to cancer education. The information is presented in ASL with open captioning and voice-over in English so it can be shared with people who are hard of hearing, as well as hearing loved ones. It was

made without competing background music to make the audio more accessible for people who are hard of hearing (<http://cancer.ucsd.edu/deafinfo>).

Members of this research team recently published the results of a blind, randomized education trial to evaluate the impact of the partnership’s new cervical cancer education video among a cohort of Deaf women who rely upon ASL as their preferred mode of communication [32]. Given the dearth of health education programs available in ASL, the women in the control group were offered the opportunity to cross over into the experimental group after completing their participation in the control group (see Fig. 1. Crossover Study Design). Once they crossed over, the women from the control group followed the same protocol as the group of women who had been randomized into the experimental group. The study showed that once the women had viewed the video, their cervical cancer knowledge increased, and the increase was statistically, significantly greater than the pre- to post-intervention knowledge change for the control group before their crossover.

The women in this study also completed an ASL version of the Multidimensional Health Locus of Control (MHLC) scales, a widely used questionnaire that measures health-related control beliefs, including IHLC. In order to determine whether internality of health control beliefs influenced the acquisition of cervical cancer knowledge, the present study assessed the relationship between IHLC and cervical cancer knowledge for the sample of participants in both the original experimental group and the

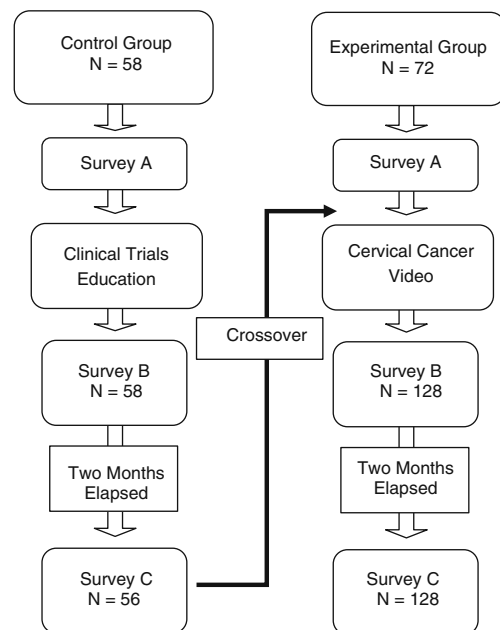


Fig. 1 Crossover study design layout [32]

crossover experimental group combined. The relationship of IHLC to both baseline cancer knowledge and acquisition of knowledge following exposure to the cervical cancer education video were analyzed.

This study tested two hypotheses:

- Hypothesis 1. Deaf women with higher IHLC will possess a significantly ($p < 0.05$) higher baseline of cervical cancer knowledge.
- Hypothesis 2. Deaf women with higher IHLC will gain and retain significantly ($p < 0.05$) more cervical cancer knowledge after a single viewing of the cervical cancer education video that was offered in ASL with open captioning.

Methods

Study Design

The study team invited adult Deaf women from Southern California who used ASL as their preferred mode of communication to participate in the evaluation of an education program intended to improve the health and well being of the Deaf community, offered in ASL and supplemented with open captioning. At baseline, 130 Deaf women completed the written human subjects consent form required to join in the study; 58 were randomized to the control group and 72 to the experimental group. Two women in the control group were lost to follow-up and could not be located to learn their reasons for dropping out of the study. When the remaining 56 control group women were invited to cross over into the experimental group after completing their time in the control group, all of them did so, resulting in 128 women in the combined experimental group.

Measures

MHLC scales The MHLC scales measure health-related control beliefs [33, 34]. The IHLC scale measures the strength of a person's belief that he or she possesses control over his or her health. An ASL version of the MHLC scales was created and recorded on videotape via forward and backward translation and reconciliation [35] and validated [36]. As the result of confirmatory factor analysis that was conducted to establish the validity of the ASL version of the MHLC for use with members of the Deaf community, one of the original items (i.e., "When I get sick, I am to blame") was removed from scoring of the IHLC subscale due to poor loading on the scale [36]. Thus, the IHLC scale score used in this study was based on five rather than

the original six items. Each item is rated on a 6-point scale from 1 = "strongly disagree" to 6 = "strongly agree," for a total IHLC score ranging from 5 to 30 points, with higher scores representing more internal control over health.

Cervical Cancer Knowledge Knowledge about cervical cancer was measured using a 13-question survey [6]. Five questions asked about general knowledge of cancer (e.g., Which cancer occurs the most often in women?); an additional eight true/false items tested knowledge about cancer and cervical cancer screening (e.g., Human papillomavirus or HPV is the virus that causes most cases of cervical cancer). A total score, representing the number of items answered correctly, was generated and used in the analysis. This total score has demonstrated validity (i.e., sensitivity to change) in the randomized controlled trial [6].

Statistical Analyses

For purposes of analysis, higher and lower IHLC groups were created, based on a median split of the data for the IHLC scale (median=25). Thus, those participants who scored 25 or above were deemed to have higher IHLC, and those scoring 24 or below were considered to have lower IHLC. Because of restricted range, this latter group of participants could not be considered to be truly low in IHLC; rather, the "lower" group average falls at about the midpoint of the scale, reflecting moderate internality of health control. A mixed model analysis was performed to analyze the repeated measures data of cervical cancer knowledge at baseline (i.e., first wave of data collection for all participants), at Time Two (i.e., immediately following the video intervention), and again at Time Three (i.e., 2 months after participants viewed the cervical cancer video intervention). Analyses were completed in SPSS 15 (Version 1.0). First, the main effect of higher IHLC (coded as values ≥ 25) relative to lower IHLC (coded as values ≤ 24) was examined in relation to participants' baseline cervical cancer knowledge. The main effects of IHLC and time on cervical cancer knowledge at Time Two and Time Three were examined, with the significance of the interaction of time and IHLC of primary interest.

Results

Sample Description

The ages of the participants ranged from 18 to 93 (mean age=40.02; SD=16.28). Approximately 1.6% of the women did not complete high school, 34.9% completed high

school, 30.2% completed some college, 18.5% completed college, and 14.6% completed more than college. The ethnicity of the sample was Caucasian (58.1%), Hispanic (15.5%), Asian/Pacific Islander (9.3%), African American (5.4%), mixed (4.7%), and other (7.0%). IHLC scores ranged from 12 to 30 on the scale, with participants overall scoring an average of 24.49 (SD=3.55).

In mixed model analysis, IHLC did not predict higher baseline cervical cancer knowledge [$b=0.241$; $F(218.29)=0.540$, $p=0.463$]; women with higher IHLC did not know more about cervical cancer at entry into the study. Also, the interaction of time and IHLC was not significant: IHLC did not predict attainment of more cervical cancer knowledge across time [$b=-0.034$; $F(190.99)=0.026$, $p=0.871$]. Having higher IHLC did not significantly predict increased cervical cancer knowledge immediately after watching the cervical cancer video [$b=0.208$; $F(96.28)=0.667$, $p=0.416$], or at 2 months following the video [$b=0.174$; $F(125.604)=0.286$, $p=0.594$]. There was a significant main effect of time [$b=0.553$; $F(189.81)=13.966$, $p<0.001$]. The mean of cervical cancer knowledge at baseline ($M=9.46$, $SD=1.78$) was significantly increased at Time Two [$M=11.34$, $SD=1.48$; $F(255)=5.273$, $p=0.022$], independent of IHLC. However, in this mixed model analysis, there was no significant difference in knowledge at 2-month follow-up ($M=10.44$, $SD=1.68$) compared to baseline [$F(252)=0.594$, $p=0.442$], or immediately post-intervention [$F(251)=2.25$, $p=0.134$].

Discussion

Deaf women face greater challenges in accessing health information than women without a hearing deficit [7, 8]. They have fewer opportunities to access health knowledge in ASL, and medical providers lack a cultural understanding of this population and its barriers in accessing health information [8, 13, 14, 16, 17]. The Deaf community advocacy leaders in this partnership had expressed the concern that Deaf women may have significantly less access to cancer knowledge and care than hearing women. The ASL cervical cancer education video aimed to address that concern by delivering cancer information in a medium that is easy for this community to assimilate. By administering the MHLC as part of the research design, it was possible to examine the question of whether Deaf women's strength of belief in personal control over their health (i.e., internal health locus of control) would influence their response to the cervical cancer education video.

The results suggested that there was no demonstrable effect of internal health control beliefs on Deaf women's baseline cervical cancer knowledge or knowledge gained after watching the video. IHLC predicted neither baseline levels of cervical cancer knowledge nor knowledge

acquisition for Deaf women who viewed the cervical cancer video. However, as this study showed, the women did show increases in knowledge as a result of the educational intervention, supporting the premise that providing education in ASL would be beneficial for the Deaf women.

Although the MHLC is frequently applied to the study of health knowledge and behaviors, in this study, IHLC did not explain the variability in health knowledge among participants, nor did it predict acquisition or retention of health information. However, most participants were quite high on IHLC. A median split was used to characterize participants with higher versus lower IHLC. This is a commonly used method of dividing samples, but it has limitations, especially when scores are negatively skewed, as they were in this sample. Therefore, it is possible that significant relationships between IHLC and health knowledge might be found in a sample with greater variability (i.e., including participants who were more truly external).

This study had several limitations. The sample was relatively small, drawn from a single geographic region, and as with most research studies, the participants were more highly educated than the overall Deaf community. The study did not analyze issues, such as previous experiences with the medical system and demographic factors that can influence health control orientation and behaviors [34]. Also, due to the short time frame, the fairly wide variation in the time until recommended repeat screening based on medical and sexual history, and the lack of data regarding participants' cervical cancer screening practices prior to the study, the study did not assess whether increased knowledge led to improvements in screening practices.

The Deaf community is one of the minority populations frequently neglected in health promotion efforts [20] and research studies. As a result, the Deaf community's concerns, including less than optimal access to health information and care, are rarely addressed. This study showed the importance of conducting research on individual minority communities, especially the Deaf community, rather than assuming that results are translatable to diverse populations. It is increasingly being recognized that members of the Deaf community need to be offered health education material in a way that caters to their linguistic and cultural preferences. Such attention will ultimately empower them to take greater control of their health [15, 16].

Conclusion

IHLC did not predict baseline knowledge or knowledge acquisition or retention for Deaf women who viewed a

cervical cancer education video. Because the women were able to gain knowledge from an ASL video regardless of their IHLC, IHLC may not be an essential consideration when designing a cancer education program for Deaf women. However, now that there is a validated version of the MHLC in ASL, future studies should evaluate the impact of IHLC on cancer knowledge acquisition and retention with samples that have greater variability on IHLC, as well as examine other types of health-related control beliefs.

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