

Bringing prostate cancer education to deaf men[☆]

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Abstract

Introduction: A review of the scientific literature yielded no examples of programs that were designed to give deaf men access to information about prostate cancer, early detection, and treatment. The community's diverse linguistic abilities, multiple preferences for receiving information, and the small size of the community, create additional challenges for health educators. **Materials and methods:** A prostate cancer education program was adapted for deaf men ($N = 121$), with the goal of creating a single program that could meet the educational needs of this diverse community. The program was evaluated using baseline, post-test, and two-month follow-up surveys, plus focus group discussions. **Results:** Overall, baseline knowledge about prostate cancer and awareness of the screening options for the early detection of prostate cancer increased significantly at post-test and this gain was maintained at the two-month follow-up. While prostate-specific antigen (PSA) screening and digital rectal exams also increased among men 50 and older, the increase was not statistically significant, possibly a consequence of the small sample size. Participants' reported their preferred methods of communication. Greater knowledge gains were demonstrated among those who preferred communications via American Sign Language (ASL) versus English-based communications. **Conclusion:** Cancer education programs offered in ASL can help address health knowledge disparities and that in turn can contribute to alleviating these disparities. Clinicians and health educators can help raise the deaf community's health awareness through programs such as this one, which ultimately evolved into the Internet accessible ASL video: Prostate Cancer: Know Your Options.

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1. Introduction

According to the CDC, 35 million Americans have hearing losses that range from moderate to profound [1,2]. Within this larger group, is a considerably smaller subset of people who self-identify as members of the deaf community as a result of their culture and language (American Sign Language (ASL)). While no exact census figure exists for this community, the deaf affinity organizations estimate the number to range from 550,000 to one million people in the United States and Canada [3].

While ASL is the fourth most commonly used language in the U.S. and the primary language within the deaf community, few health care professionals are proficient at communicating in ASL or culturally competent when communicating with deaf patients [4–6]. As a result, members of the deaf community experience significant linguistic and cultural barriers to accessing health information and care. Compounding this problem is the fact that people who become deaf early in life learn English as a second language without the benefit of aural reinforcement. This often leads to literacy levels that limit the deaf community's ability to access health information that is disseminated in oral and written English [4,6–9]. Further, while ASL is the language that is most accessible to this community, individual members possess varying levels of proficiency. The first step to addressing the health disparities that result from these barriers is to adapt traditional mainstream health education programs so they can be accessed by deaf community members even when their English and ASL skills are limited [9,10].

Following exposure to a breast cancer education program for deaf women, the participants recommended that a similar program be developed for the community's men [10]. Prostate cancer, the most common form of life threatening cancer in American men over the age of 50, was an appropriate topic to address. An estimated 30,000 deaths occur each year from this disease [11]. The goals of this pilot study were to create and evaluate a prostate cancer education program for deaf men that would: 1) meet the deaf community's diverse cultural and linguistic considerations, as well as their expressed preferences for methods of delivering information and 2) increase their health maintenance knowledge and awareness of screening options related to early prostate cancer detection, as well as their treatment options, including clinical trials.

2. Materials and methods

Hypothesis: After participating in a prostate cancer education program that has been adapted to address deaf men's diverse cultural and linguistic considerations, as well as their expressed preferences for methods of delivering information, deaf men will demonstrate a significant ($p \leq .05$) increase over their baseline knowledge of the subject.

A convenience sample of 121 deaf men was recruited using networking and "snowball" recruitment strategies [12,13]. To participate, men had to be at least 18 years of age, live in Southern California, identify themselves as part of the deaf community, and have ASL skills at a level they deemed sufficiently proficient to take a class provided entirely in ASL. While this is a disease of older men, health educators who follow the social cognitive theory as the framework of their behavioral change interventions recognize that information disseminated from a trusted source is a most powerful motivator of behavioral change [14,15]. For this reason, the researchers opted to include people of all ages so they could be empowered to disseminate this information to others in their community.

Using the Health Belief Model and the Stages of Change Model, the authors also hypothesized that providing increased access to health information and care would be a driving element that determined the likelihood of behavioral change [16–19]. Towards this goal, the research team developed a PowerPoint® presentation to promote deaf men's awareness of prostate cancer and the available screening and treatment options. Topics included: risk factors; early detection methods; signs and symptoms; treatment options; clinical trials; and additional sources of reliable information. Using insights gained from earlier experiences working with deaf women, the number of graphic slides was doubled, summation slides were added, and medical terms were defined in easy-to-understand English to promote optimal understanding [10]. Consistent with Social Cognitive Theory, the women had also recommended training deaf men to teach other deaf men about prostate cancer using ASL and an accompanying PowerPoint® presentation to guide them [14,15]. A "train-the-trainer" model was, therefore, selected as the foundation for the program's method of disseminating information.

Before the educational intervention, participants completed an IRB-approved consent document and a baseline survey consisting of both open and closed ended questions. Participants answered questions related to socio-demographic data, communication preferences, knowledge of general medical information, barriers to health care, and participants' baseline knowledge, attitudes, and screening practices related to prostate cancer. All participants were offered the option of having the consent document and questionnaire translated into ASL. Consenting and surveying each individual in ASL, using a forward and backward translation, was the preferred method [20,21]. However, because there is no written version of ASL, this process would need to be captured on videotape. IRB permission to consent participants using a videotaped version of the consent document was requested and denied on the grounds that participants needed to receive a live one-on-one translation of the document. As a result, participants received on-the-fly translations of the consenting process and surveys.

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