

Community/academic partnered cancer prevention and control research among the racially/ethnically diverse D/deaf population

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Health Disparities Research at the Intersection of Race, Ethnicity and Disability:

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Who are the D/deaf and hard of hearing ?

- Hearing Loss: approximately 16% of U.S. adults
36-37 million persons
- Heterogeneous population:
 - Demographic characteristics, age deafened, degree of hearing loss
 - Identification with the Deaf community (estimated at half to one million persons), a recognized minority community with a unique language, culture and history -- Deaf, deaf, hard of hearing
 - Language Usage: American Sign Language (ASL), Signed English, finger spelling, lip-reading/oral, home signs
 - English literacy: adults on average read at 4th grade level
 - Frequently poor/employment limitations

Why this program of research?

- D/deaf people experience:
 - inadequate access to health information in clinical settings, media, written materials
 - limited research participation (especially among D/deaf persons with lower levels of education and from racial and ethnic minority groups)
 - few tailored evidence-based comprehensive educational programs
 - significant gaps in health knowledge and information, poor preventive health behaviors, and barriers to adequate services and resources including with respect to cancer prevention and control

A 15+ Year Community-Academic Research Partnership

Partners

- Center for Cancer Prevention and Control Research, Fielding School of Public Health and Jonsson Comprehensive Cancer Center, University of California, Los Angeles (UCLA)
- GLAD - Greater Los Angeles Agency on Deafness, Inc.
- California School for the Deaf, Fremont
- Schools, agencies, organizations, individuals in service to the D/deaf population (California and elsewhere)

Program Focus

- Two community cancer prevention concerns:
 - tobacco use prevention education among youth
 - breast cancer education among D/deaf women

Funding

- California's Tobacco Related Diseases Research Program (TRDRP) 1997-2010
- California's Breast Cancer Research Program (CBCRP) 2001-2010
- Susan G. Komen Foundation (Race for the Cure) 2003-2007

Tobacco Prevention Research

Why a focus among D/deaf youth?

- Tobacco use is a major public health problem responsible for over 430,000 U.S. deaths annually
- Use primarily begins among youth; addiction makes cessation difficult
- Concern that D/deaf youth are at increased risk
 - issues of social acceptance, low self esteem, communication, academic difficulties
- Lack of research and a lack of tailored evidence-based programs for D/deaf youth

Tobacco Prevention Research Survey and In-Depth Interviews

- Survey research (1997)
 - 467 students: Middle and High School (n=226) College (n=241)
 - 76.5% (High School) and 61.4% (College) from racial and ethnic minority groups
 - Interactive multi-media computer video technology developed specifically for use among the D/deaf
[ASL, Signed English (SE), Speech Reading (SR)]
 - Example of English/ASL “translation” (gloss)
 - English: Have you ever seen antismoking messages or signs made especially for deaf/hard of hearing people?
 - ASL: Finish you see [point] deaf signing, what, stop-smoking messages?
 - Back Have you seen deaf people communicate with information
 - Translation: against smoking?
- Qualitative in-depth interviews (1999) (40 students)



Tobacco Prevention Research Survey and Interview Findings

- Survey:
 - Middle/ High School students: 45% ever smoked, 26% did not know second hand smoke exposure was dangerous, 15% no tobacco prevention education at any grade level (greater in mainstream than Schools for the Deaf)
 - College students: 65% ever smoked, 16% did not know smoking causes cancer
 - 84% saw a physician in prior year
in prior year 35% were told by a physician why it was bad to smoke
- In-depth interviews:
 - More current smoking than reported on survey
 - Aware of cigarette brands and marketing
 - Never exposed to tailored anti-tobacco message
 - Confusion about advertising and anti-tobacco messages

The image features two cowboys on horseback, silhouetted against a vibrant orange and yellow sunset sky. They are positioned in the center of the frame, facing away from the viewer. The scene is set in a rural, open field with wooden fences visible on either side. The overall mood is nostalgic and evocative.

I miss my lung, Bob.

California Department Of Health Services.
Funded By The Tobacco Tax Initiative.



煙草殺人 - 不要受騙

不應宣傳、美化或資助煙草產品

5月31日  世界不吸煙日

Tobacco Prevention Research Intervention Studies

- Develop a tailored curriculum (2001-2002)
- Quasi-experimental randomized controlled trial of the curriculum (2003-2007) (3 years)
 - 4 Schools for the Deaf in 3 states
 - 618 Middle and high school youth (baseline)
61.8% from racial and ethnic minority groups
 - 166 faculty (survey at baseline, end of study)
- Dissemination (ongoing)(2010)

Tobacco Prevention Research

Baseline Characteristics

- Baseline Faculty Survey (n=166)
 - 26% had no school-wide tobacco program
 - 14% taught tobacco prevention in prior year
 - Among these faculty, barriers to tobacco prevention education:
 - 61% lack of tailored material
 - 48% lack of time, 44% lack of training
- Baseline Student Survey (n = 618)

At the four schools between 9.6% and 22.7% reported past month smoking

Tobacco Prevention Research Intervention/Curriculum



Hands Off Tobacco!

An
Anti-Tobacco
Program
for Deaf Youth

Tobacco Prevention Research Findings from Intervention Studies

- The tailored curriculum made a difference in exposure to anti-tobacco educational programming and tobacco-related knowledge and behavior.
- No baseline intervention/control group differences; at follow-up a statistically significant
 - increase in treatment (not control) group receipt of programming and tobacco-related knowledge
 - decrease in current tobacco use in treatment (not control) group.

Breast Cancer Research Pilot Study

- In depth interviews among 68 women ages 40-88; 7 breast cancer survivors (2001-2003)
 - 65% \leq high school (HS); 72% pre-lingually deafened
 - 27% from racial and ethnic minority groups
- Findings
 - Incomplete regular breast cancer screening
Past year mammogram: \leq HS 41.9%, \geq HS 80.0%
Past year CBE: 56.0% 71.4%
 - Insufficient/ incorrect breast cancer knowledge
Breast cancer can result from: exposure to other people (catching it “like a cold...from germs”), sports activities (“jumping around”), wearing tight clothing, having too many children, breast feeding, taking birth control pills. Only 3 women knew age was a breast cancer risk factor.

Breast Cancer Research Pilot Study

- Findings (continued)
 - Lack of access to adequate information
 - English often difficult to understand; no reports of ever seeing breast health information tailored for D/deaf women; TV captioning not always available; reports of no computer to obtain health information
 - Friends/ family can convey incorrect information
 - Unwilling to discuss breast cancer (“too private” “that is how Deaf culture is” “D/deaf women are not educated about how important breast health is and won’t talk about it”)
 - Inadequate/unsatisfactory communication with physician
 - “My doctor refuses to have an interpreter...”
 - “The way I was treated made me feel as if they thought I was silly or stupid”
 - “I feel sometimes that they are not giving me all the information”

Breast Cancer Research Intervention Studies

Goal: Develop, test, disseminate a tailored breast cancer educational program for D/deaf and hard of hearing women

- Build on prior research and videos
 - English language information, Pilot Study
 - Existing DVDs: Understanding Breast Health? Women Can!, Advocate Illinois Masonic Behavioral, Health Services (Chicago); Breast Cancer Education. Every Deaf and Hard of Hearing Woman Counts! Moores Cancer Center, UCSD (G. Sadler, Ph.D.)
- Utilize a conceptual/theoretical model: Health Behavior Framework
- Ensure access for women with all levels of education
- Include women from diverse racial and ethnic groups
- Inform interventions for other underserved low literacy minority groups

Breast Cancer Research Intervention Studies

- Demonstration Study
 - 45 women 40+ yrs old, 23 breast cancer survivors
 - All participants received breast cancer educational program (DVD, brochure, small group workshops)
 - Baseline, post intervention, 6 mo follow-up surveys
- RCT
 - 209 women, 40+ yrs old, \leq high school education, racial and ethnic diversity
 - Treatment group: breast cancer program
Control group: cancer education (tobacco, nutrition, sun exposure power point)
 - Baseline, post-program, 12 mo follow-up surveys

Breast Cancer Research

RCT Baseline Characteristics

- Deafened: 83.6% prelingual deafened
- Race/Ethnicity: 48.2% racial and ethnic minority groups (22.3% Latina)
- Education: 32.1% < High School
41.1% H.S., GED, Certificate
26.8% Some college, community college, vocational, business, trade school
- Family Income: 83.8% \leq \$30,000
- Age: 44.0% >60 (14.5% > 75)
- Insured: 94.2% (79.5% Medicare/Medi-Cal)
- Weight: 65.2% overweight or obese

Breast Cancer Research

RCT Baseline Characteristics

- Most women (83.2%) saw doctor in past year and were satisfied (72.8%) with communication with doctor
- 94.2% insured; available California programs
- 57.3% mammography in prior two years
 - No physician referral most frequent reason for non compliance (43.5%).
 - Cost/no insurance also noted (13.9%)
 - Lower than for insured women in U.S. or California
 - Statistically significant variations by education, race/ethnicity, income, type of insurance
- 55.0% CBE in prior two years

Breast Cancer Research

RCT Baseline Characteristics

- Gaps in knowledge
 - Incorrect choices of risk factors:
exercising a lot/jumping around, breast feeding,
wearing tight bras/ other clothing,
hitting/ bumping breasts
 - Failure to recognize some known risk factors:
age, early period/onset of menarche, late menopause,
being obese
 - Correctly identified goal of: mammography (64.3%),
biopsy (51.8%), chemotherapy (34.5%)



Signs of Awareness

**A Visual Guide to
Breast Cancer
for Deaf and
Hard of Hearing Women**



Jonsson Comprehensive Cancer Center
Division of Cancer Prevention and Control Research



Breast Cancer Research Intervention

“Signs of Awareness: A Visual Guide to Breast Cancer for the Deaf and Hard of Hearing”

- Small group format, trained deaf health educator, visual aids
- Tailored DVD
 - “Chapter” book – modular elements/ sidebars/menu
 - Comprehensive content
 - Sequential not simultaneous presentation
 - ASL, written captions, voice over, finger spelling
 - Animation, visual elements
 - Narration by Deaf actress, Deaf physician
 - Participation by D/deaf survivors/ community members
 - Content: breast cancer, empowerment, overcoming communication barriers, participation in breast health advocacy, use of resources
- Tailored written “companion” booklet: emphasis on visual elements

Breast Cancer Research Challenges

- Create comprehensive understandable content for D/deaf women with diverse education levels
- Translating complex concepts into ASL
- Creating visual images to convey complex concepts
- Alternating ASL messages and visual images; simultaneous communication is not possible
- Crafting/ administering survey instruments that convey complex concepts
- Next steps: analyze and disseminate our results and programs

Research Collaborators

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