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 Study 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 against smoking?
    - 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
I miss my lung, Bob.
烟草杀人 - 不要受骗

不应宣传、美化或资助烟草产品

5月31日 世界无烟日
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 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% ≤ high school (HS); 72% pre-lingually deafened
  - 27% from racial and ethnic minority groups

• Findings
  - Incomplete regular breast cancer screening
    Past year mammogram: ≤ HS 41.9%, > 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, < 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% ≤ $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
Breast Cancer Research Intervention

• 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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