Does Digital Storytelling Improve Cancer Prevention and Decrease Medical Mistrust in American Indians?

Emily A. Haozous, PhD, RN, FAAN
UNM College of Nursing

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Michele Suina, PhD
Albuquerque Area State Tribal Epidemiology Center

Charles Neher, BS
Research Assistant
University of New Mexico Health Sciences Center

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The purpose of this project was to test a digital storytelling intervention while measuring for change in medical mistrust among urban-dwelling American Indians and Alaska Natives

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Background

- Cancer disparities
- Medical mistrust
- Digital Stories

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Control Group

Cancer Facts

American Indians/Alaska Natives and Cancer

WHO WE ARE

We are among the estimated 4.5 million people who are classified as American Indian and Alaska Natives.[1] As a group we comprise 1.5 percent of the total U.S. population but are scattered over 560 federal and over 100 State recognized tribes, of which each has its own unique culture.[2] Not surprisingly, there are great diversities within our communities with regard to political, social, cultural, and spiritual beliefs and customs.

While we continue to live on designated lands or reservations, over the past three decades, many of us have increasingly relocated from rural communities and reservations into urban centers. Our "invisible" urban population now makes up more than half of all American Indians and Alaska Natives living in the United States.[3]

There are well-documented differences that exist between urban American Indians, Alaska Natives, and the rest of the American Indian population as a whole in terms of access to our healthcare, our health risk behaviors, threats to our health, and our health outcomes.[3]

As American Indians and Alaska Natives, we also suffer from greater health disparities compared with the general population. These disparities include higher rates of tobacco use, infant mortality, delayed prenatal care, violence, attempted suicide, and deaths due to diabetes, accidents and chronic liver disease.[4-7] Because of our higher mortality rate, we are younger as a group than the rest of the U.S. population. Likewise, as American Indians and Alaska Natives and US citizens we continue to be among the poorest, with 1 in 4 living below the poverty level compared with 1 in 10 of the non-Hispanic/Latino whites in the general United States population.[8]

Causes/Etiology

- Skin cancer is relatively rare in American Indians, but when it does occur, it often has an atypical presentation leading to delays in diagnosis and treatment and a higher mortality rate.[9]
- In 2005, 32% of American Indian adults smoked more than any other ethnic group. However, these smoking rates vary by region and state. They are highest in Alaska (45.1%) and the Northern Plains (44.2%) and are lowest in the Southwest.[11]
- American Indians, but not Alaska Natives, have a high incidence rate of HPV most often triggered by high-risk oncogenic serotypes not covered by the new HPV vaccine.[13]
- Not only does gall bladder carcinoma begin earlier in American Indians (age 55) than Hispanics (age 60) and non-Hispanic whites (age 65), American Indians led all ethnicities in incidence rate among both male (7.8 per 100,000) and female (14.5 per 1000,000) categories.[29]

Screening

- Screening rates for breast, colorectal, prostate, and cervical cancers are lower among American Indians/Alaska Natives than non-Hispanic/Latino whites.[10]
- Hispanic/Latinos and American Indians/Alaska Natives are the least likely ethnic groups to have a college education, most likely to have family incomes below 200% of the poverty level, and most likely to have no health insurance coverage, all of which are factors associated with low rates of cancer screening.[11]
- American Indians/Alaska Natives are less likely to receive PAP smears, which contributes to their having the highest cervical cancer mortality of any population in the United States.[13]
- The highest proportion of men receiving no treatment for prostate cancer was observed in Native Americans (40%) when compared to non-Hispanic/Latino whites (25%).[14]
- Of the American Indian/Alaska Native women aged 18 and over in California, 91% have had at least one Pap test, and 83% reported a Pap test within the past three years.[15]
- More than 68% of American Indian/Alaska Native women aged 40 and over in California had a mammogram within the past two years, however, only 1 in 10 American Indian/Alaska Native women 40 years and older, reported never having a mammogram.[15]

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ICC Intercultural Cancer Council

Project Director
Nicholas K. Iammarino, PhD, CHES
Research Assistant
Mohammed Ansar Ahmed
Prem Ramkumar

Intervention Group

Methods

- Instruments
  - Medical Mistrust Scale
  - Intent to Receive Screening
- Analysis
  - Spearman's rank-order correlation
  - Chi-square
  - Fisher's exact test

Methods

- Eligibility Criteria
  - Adults ≥18
  - Self-identified American Indian/Alaska Native
  - Able to give consent
  - Outpatient AIAN – serving clinic
- Randomization
  - First block: control
  - 2 week wash-out
  - Second block: intervention

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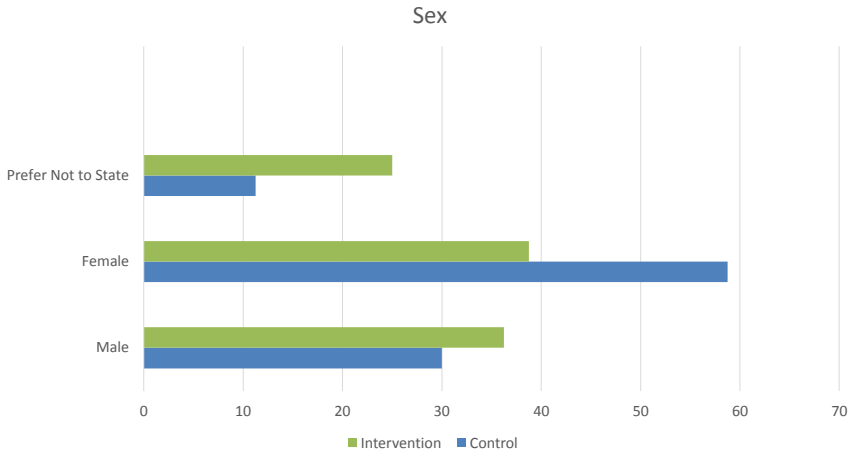
Results



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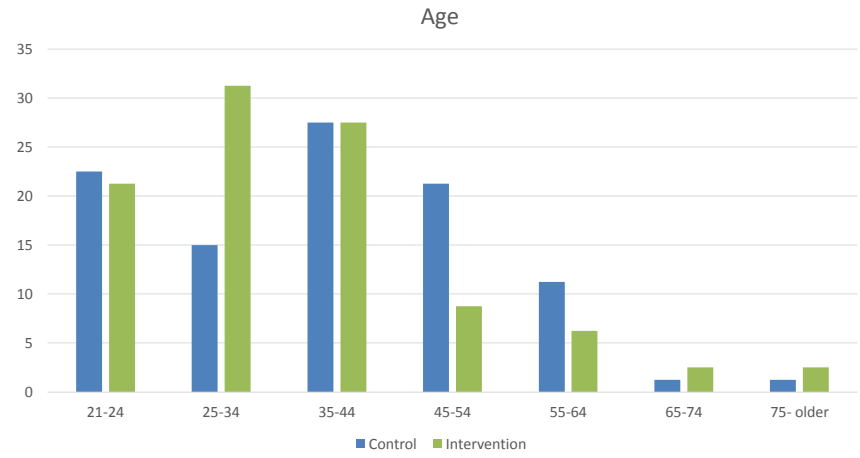
Results



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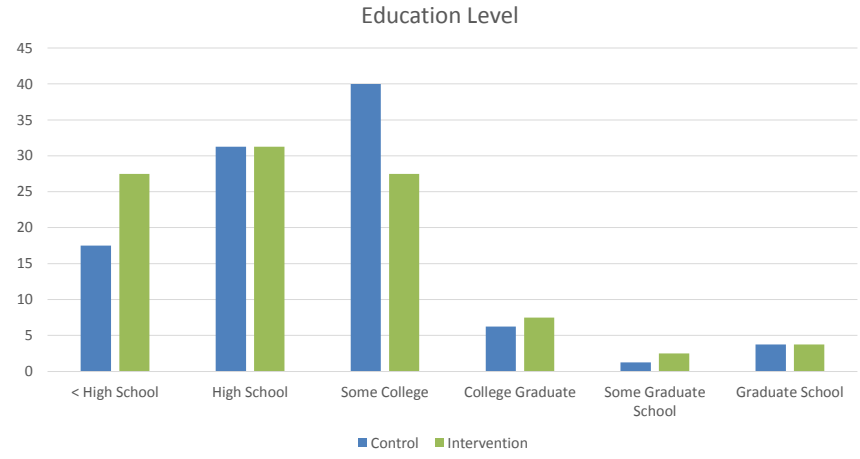

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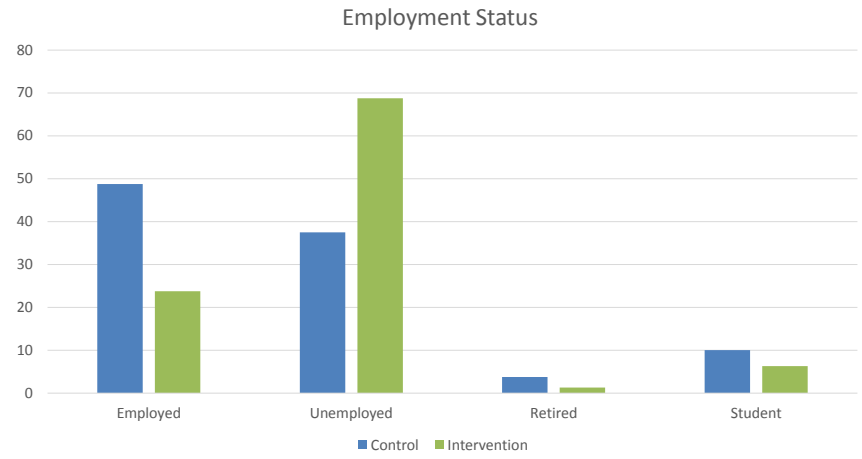
Results



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Results

- Medical Mistrust Scale
- H_0: There will be no measureable difference on the Medical Mistrust or Intent to Receive Screening items between the control and intervention groups

- Found significant difference in only 4 responses on survey (p=<0.05)
  - Differences were in favor of control group

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Results

Variable	rho	Mean	SD	p-value
Q1	**-0.264**	**2.83125**	**1.117**	**0.0007**
Q2	0.0544	2.11875	0.993	0.4943
Q3	-0.0118	2.9625	1.127	0.8826
Q4	-0.0017	2.60625	1.254	0.9833
Q5	**-0.1436**	**3.18125**	**1.283**	**0.0701**
Q6	-0.1147	3.2375	1.276	0.1485
Q7	**-0.194**	**3.45**	**1.212**	**0.014**
Q8	**-0.4496**	**1.86875**	**0.817**	**0**
Q9	-0.0993	3.71875	1.156	0.2118
Q10	0.0267	2.13125	0.998	0.7375
Q11	0.065	2.14375	0.875	0.4145
Q12	0.1038	1.98125	0.85	0.1917
Q13	0.0044	2.15625	0.968	0.9557

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Significant items

- Q1: Hospitals and clinics often want to know more about your personal business than they really need to know. (mistrust)
- Q5: I worry that doctors and nurses will do experimental studies on me without telling or asking me. (p= 0.07) (trust)
- Q7: I have put off getting medical care when I have had health problems because I do not trust doctors and nurses. (trust)
- Q8: I usually trust doctors (trust)

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Intent to receive screening

Questionnaire Item	Mean	SD	p-value
Have you ever had a cancer screening test in the past?	**0.3741**	**0.4856**	**0.0394**
How likely is it you will ask for cancer screening in the next 6 months?	2.675	1.2815	0.539
How likely is it you will ask for cancer screening in the next 12 months?	2.594	1.199	0.2637

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Discussion

- Hoped to find higher levels of trust with the intervention group
  - Brochure was depersonalized and safe
  - Digital Story possibly triggered mistrust

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Limitations

- Not a pre-post design
- Contamination

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Future Research

- Established feasibility of tablet computers for data collection in a high-traffic urban clinic
- Digital Storytelling has emotional power for people making stories
- Mediation of medical mistrust requires further investigation

ehaozous@salud.unm.edu

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