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Melany Cueva

Alaska Native Tribal Health Consortium

Regina Kuhnley

Alaska Native Tribal Health Consortium

Laura J. Revels

University of Washington

Anne P. Lanier

Alaska Native Tribal Health Consortium

Mark Digman

See next page for additional authors

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Author Information

Melany Cueva, Regina Kuhnley, Laura J. Revels, Anne P. Lanier, and Mark Digman

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Melany Cueva

Alaska Native Tribal Health Consortium

Regina Kuhnley

Alaska Native Tribal Health Consortium

Laura J. Revels

University of Washington

Anne P. Lanier

Alaska Native Tribal Health Consortium

Mark Dignan

Markey Cancer Center

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Abstract: Between May 2009 and October 2010, four week-long cancer education courses were provided for 35 community health workers (CHWs) from throughout Alaska. This project explored how cancer-related, digital stories created by CHWs supported their learning journey and provided a tool to share cancer health messages with people in their communities. Digital storytelling combines storytelling with computer-based technology to bring the power of the media to community members. End-of-course written evaluations and qualitative interviews revealed that combining digital storytelling with cancer education was feasible, culturally relevant, and enhanced participant learning.

“I have seen too many people die of cancer. I believe in early screening. I know that it won’t detect all cancer or prevent all cancer deaths but this will decrease some. After watching my story I hope people think about getting screened. Think about the people that love you, who will be the one caring for you. Cancer affects everybody – not just the person who has it.”
“We each have a story to tell. We are from all over Alaska with unique stories.”~ Participants

Alaska is the largest state in the US comprising one-fifth of the landmass of the contiguous 48 states. Alaska Native people represent approximately 19% of the state population, the largest proportion of Native American people in any state in the U.S. Approximately 60% of Alaska Native people live in 178 rural communities not connected to a road system. Because Alaska communities are small (20 to 1500 people) even a single cancer diagnosis has a huge impact on the community.

Cancer, considered a rare disease among Alaska Native people in the 1950s, became the leading cause of death in the 1990s and remains so today. In the five-year period from 1999 to

2003 the Alaska Native death rate from cancer was 25% higher than for U.S. Whites. A comparison of age-adjusted incidence rates for 1969-73 and 1999-03 shows a cancer increase of 34%. Over the same two time periods, the rates for specific cancer sites increased dramatically: breast (207%), lung (146%), prostate (75%), and colorectal (24%). Comparison of Alaska Native and U.S. White five-year survival rates (1992-2002) show that for all cancers combined, Alaska Native people have a 17% lower five-year survival rate (Lanier, Maxwell, & Homan, 2006).

Alaska Native people have high rates of many risk factors for cancer. Based on 2007 adult Alaska Behavioral Risk Factor Surveillance System data, 38% of Alaska Native people were current smokers, 83% reported no moderate physical activity, 79% consumed less than 5 servings of fruits and vegetables, and 72% reported being overweight (Alaska BRFS, 2007).

Community health workers (CHWs), approximately 600 Community Health Aides/Practitioners, 120 Behavioral Health Aides, and Community Health Representatives, are community residents chosen by their tribes to be trained to provide preventive, primary, emergency, chronic, and acute health care. CHWs receive basic training following a standardized curriculum with only a few hours devoted to cancer education. Equipped with culturally appropriate cancer education and resources CHWs are in an ideal position to educate community residents about cancer risk reduction behaviors, advocate and arrange for recommend screening exams, recognize cancer warning signs, and make referrals for early diagnosis and treatment. As community members, CHWs understand the social, political, cultural, and linguistic context of their communities to support individual as well as community wellness.

Purpose

This project explored how cancer-related digital stories created by Alaska's village-based CHWs as part of a five-day cancer education course enhanced learning and provided a tool to share cancer health messages with people in their communities. Digital storytelling combines a person's recorded voice with their choice of pictures and music to bring the power of the media into the voices and hands of community members. Since its inception in 1994, digital storytelling has gained momentum as a popular education social advocacy tool (Lambert, 2009). No peer-reviewed literature was found that reports the efficacy of digital storytelling as a pathway for cancer prevention and control. Culturally respectful ways of sharing cancer-related health messages that speak to people's hearts and minds are essential to empower wellness ways among Alaska's diverse Native people.

Conceptual Framework

The tradition of storytelling is part of all Alaska Native cultures (Mayo & Natives of Alaska, 2002). Within Alaska there are 229 federally recognized tribes. Stories have been used for generations to pass on traditions, life lessons, and cultural values. Elders told stories as a non-directive way for listeners to apply lessons to their own lives (Wilson, 2008, pp.27-8). The use of story embodies multiple spheres of learning. Alaska's Community Health Aides/Practitioners (CHA/Ps) identified story as a pathway for connecting people, facilitating knowledge and understanding, enhancing remembering, engendering creativity, expanding perspectives, envisioning the future, and inspiring possibilities (Cueva, Kuhnley, Lanier, & Dignan, 2007).

This project was guided by the principles of appreciative inquiry, honoring Alaska Native people's cultural strengths which value the importance of relationships and interconnected ways of knowing and being, as well as narrative inquiry which uses storytelling as a vibrant way of

knowing and understanding. Wilson (2008) stated an Indigenous methodology is a process that adheres to relational accountability which includes respect, reciprocity, and responsibility.

Design

This project included learning with and from ‘Path to Understanding Cancer’ course participants through a pre-course written application, an end-of-course written evaluation, post-course internet survey, and an extended interval in-depth interview. Details of evaluation components are coupled with findings. Cancer education participants were emailed throughout this dynamic process to celebrate their contributions, learn their experience with combining digital storytelling and cancer education, and communicate the learning journey.

‘Path to Understanding Cancer’ course description

The five-day course used the ‘Path to Understanding Cancer’ curriculum (Kuhnley & Cueva, 2010) with the addition of digital storytelling. The course included the following basic cancer content: wellness ways including lifestyle choices to decrease cancer risk or prevent cancer and recommended cancer screening exams; facts about cancer among Alaska Native people; and information about cancer diagnosis, treatment, support, and comfort measures. The course manual, ‘*Understanding Cancer*’, written in collaboration with medical providers in Alaska and CHWs includes 9 sections: 1) Self-Care, 2) Wellness Ways to Prevent and Decrease Cancer Risk, 3) Cancer and Our genes, 4) Understanding Cancer Basics, 5) Cancer Treatments: What to Expect, 6) Cancer Pain: Assessment and Management and 7) Loss, Grief and End of Life Comfort Care 8) Resources and 9) Community Activities.

Course faculty included an RN with over 12 years experience working in cancer education with Alaska Native people and an Alaska Native cancer survivor with digital storytelling expertise. Guest instructors were included to supplement content components.

Participants

Between May 2009 and October 2010, four week-long cancer education courses were provided for 35 CHWs (32 women and 3 men) from throughout Alaska. The majority of Alaska CHWs are women. Participants included 21 Alaska Native people, several of whom self-identified as being from one of the many diverse Alaska Native tribes including Athabascan (3), Aleut (6), Tlingit (2), Yupik (3), Inupiaq (4), as well as 3 American Indian, 1 Asian, and 8 Caucasian people. Ages of participants ranged as follows: 3 (19-29), 10 (30-39), 9 (40-49), 9 (50-59), and 4(60 or older).

Pre-course application summary

As part of the pre-course written application, CHWs shared ways cancer had impacted their lives and how they hoped to apply their new knowledge as a result of course participation. Community health workers were selected based upon their ability to attend the entire course, support of their regional health corporation, and their interest in learning about cancer. *“I think some people shy away from people affected by cancer being they are not sure how to act around them. I for one would like to be there for the people and their family affected by this disease.”* *“Being as busy as we are in the clinic, we don’t do much on patient education regarding prevention of illness; we mostly focus on patient education on how to treat illness. I think this will help encourage me to talk to our patients more on prevention.”*

Findings

Digital story topics

Participants' personal stories shared heartfelt experiences. Digital story topics (35) included self care (9 stories), the importance of recommended screening exams (9), tobacco cessation (6), cancer survivorship (6), and loss, grief and end-of-life comfort care (5). All course participants gave written permission for the Alaska Native Tribal Health Consortium to share their stories with other people interested in learning more about cancer and Alaska village life.

Participants related ways cancer had touched their lives. *"When you hear the word – cancer - it's a little scary—I'm a cancer survivor for 27 years. You don't have to die."* *"It felt good to get that heavy thing I've been carrying out - It was a way for me to share my grief."*

Participants shared cultural perspectives about cancer, reflecting traditional values, language, traditions, ways of knowing, intergenerational knowledge transmission and other cultural attributes. *"By sharing my story it may encourage others to share their story."* *"Storytelling makes it easier to hear the message - It touches people's hearts."*

Additionally, participants shared health messages to promote health and wellness with people in their communities. *"I wanted to share how tobacco caused a big loss [multiple family members died of cancer]. I hope by showing my story more will quit tobacco."*

After completing their digital story, each participant responded in writing to the following statements: 'I told this story because ...; and After watching my story, something I hope you think about...' Select responses follow. *"I told this story because of the pain I feel and hear about our traditional ways of living. I feel we need to return to our ancestors teaching to recognize our health. I hope people think about the difference in cultures."* *"This story is something that I have to face, I don't want to carry around that hurt and let it affect my future children...I hope my story helps others recognize that vicious cycle too and how our communities are still being affected by events from long ago."* *"People are more than their cancer - just be with them - they're not dead yet! Keep being yourself around them."* *"Life is a gift - live it to its fullest - stay healthy - get screened."* *"What we say is who we are - live each day to the fullest knowing that we're here now and we want to spend it in a good way making good memories with family and friends."* *"Even in grief there is always light-it may be hard to see but it's there."*

End-of course written evaluations

All course participants completed an anonymous three-page, written end-of-course evaluation which included check-box and open-ended questions to learn their experience with combining digital storytelling with cancer education. 100% of participants affirmed ways digital storytelling supported their learning, was culturally respectful, and increased their cancer knowledge.

Ways digital storytelling supported learning. *"By telling our own story it encouraged us to think about the subject."* *"My retention of information was greater than normal."* *"I know how to talk about cancer a lot easier. It makes it easier when you know the facts and how important it is to get screened and keep up with them. I'll be checking on the people back home."*

Ways participants felt the course was culturally respectful. *"It encouraged openness, tolerance, sensitivity."* *"We all respected each other, no one was left out."* *"I love analogies for explaining things, especially if it somehow relates to the land."* *"It is really important to know your culture and encourage activities or stories using culture and be encouraged to do so!"*

Ways participants described how the course increased their cancer knowledge. *“I came to this workshop not knowing much about cancer. I left the week knowing lots of different types of cancer and have material for reference. I will share the information with other people.”*

As a result of course participation, 86% (30/35) of respondents described ways they felt differently about cancer. *“Less fear of the unknown. It’s not as scary.” “It’s okay to say ‘Cancer’. Can talk about it now and say the word cancer. Feel more comfortable talking and learning.” “It’s okay to cry - okay to laugh. I can be more open. It is alright to grieve, share, and let go.”*

In response to the question, ‘By creating your own digital story do you feel more confident to share cancer education with people in your community?’ 94% (33/35) circled yes and 17 respondents wrote comments. *“I have more information to share plus I have the ‘courage’ - how to be there for someone and their family with cancer. More aware of survivors’ and caregivers’ feelings.” “I learned a lot and will be much more aware of family, friends, and self getting screenings and pay attention to their results. Also will offer to go with others.”*

In response to the open-ended question, ‘Will you do anything differently as a result of cancer education for you, your family, and in your work?’ participants wrote detailed information. Very few evaluations were left blank as reported below.

Participants (70% (27/35) wrote wellness changes they hoped to make as a result of course participation, including having screening exams, eating healthier, and being more physically active. *“To do a yearly physical exam - to take care of me - self-care.” “Improve diet and exercise. Walk the talk.”*

Participants (86% (30/35) reported shifts in the ways they planned to support family health which included encouraging family screening activities and eating healthier. *“To have my children get their exams. Offer to go with them for screenings.” “Pay more attention to diet. I have already started sending emails to my daughter with tips ‘5 a day is fine but 9 is divine’.”*

As reported by 80% (28/35) of participants the course strengthened their patient care practices. They described feeling more confident in their cancer knowledge and communication skills as well as being empowered to provide cancer education and support community wellness to decrease cancer risk. *“Speak out. Make sure to help people get their screening. Encourage screening.” “Create community around self care, gardening, exercising, share my story.”*

Internet survey results

In June 2010, 4 months to 1 year after course participation (courses 1-3), participants (n=24) were emailed a 10 question anonymous, internet survey (using esurveyspro) to learn about digital story use. Of the 22 participants with working email addresses, 64% (14) responded. 100% (14) of respondents identified digital stories as a helpful way to share cancer information. 13/14 participants reported showing their story on average five times, to an average of 26 people, ranging from 2-40 people, including family, co-workers, friends, community members, youth, elders, and patients. Community sharing activities included doing community presentations, school presentations, health fairs, and posting their stories on the web.

Select responses to the open-ended question, ‘What else do you want us to know about digital storytelling to support learning and as a way to share cancer information?’ are: *“Digital storytelling can capture viewers’ attention and get a message across quickly.” “Wonderful tool – a way to share personal stories in a method that resonates with the society of today.” “We live in such a technology based world now that digital storytelling naturally fits as a way to effectively tell our story.” “Digital stories have a personal perspective that people understand.”*

Post-course Outreach Efforts

Approximately eight months after course completion, participants (course 1-3) were invited by email and/or letter to participate in a telephone interview. 63% (15 /24) of participants shared ideas about combining digital storytelling with cancer education. An adult educator not involved in course instruction conducted the follow-up interviews and transcribed the audio tapes. Thirteen people expressed their ideas during a telephone interview conversation which ranged from 40 minutes to an hour depending upon the person and how much they wanted us to know and understand about the impact of digital storytelling on their life. Two course participants chose to share their ideas via email.

Several themes emerged as participants shared their experiences about combining digital storytelling with the 'Path to Understanding Cancer' course as noted by the course instructor and the interviewer. In general, participants reported increased cancer knowledge and confidence to talk about cancer and described feelings of healing and renewal associated with experiencing the course.

Participants shared powerful ways that the process of telling, creating, and sharing their story had transformed their wellness ways for themselves, their families, and in their work.

“Digital stories allowed me to talk about things that are important – meaningful - in a safe way – it helped open conversations about things that are hard to talk about.”

Participants reported ways digital storytelling made a difference in their personal health practices. *“Well just from making my digital story it made me think about my healthcare, because I’m the type of person that doesn’t like to go to the doctor. And I’ve thought about that and I actually went and I had screening done.” “Made me think about my eating habits and I tried to improve that, and my husband is trying also.” “This course was a wonderful opportunity for healing for me - helped me deal with my grief.”*

Participants shared ways digital storytelling supported family health. *“I spoke with my siblings who were surprised-they didn’t have information about Alaska Native people having a high risk of cancer and didn’t realize mother had colon cancer and that having a family member, a first-degree relative who had colon cancer increased your risk. One family member quit smoking.” “I scheduled appointments for me and my husband to get colonoscopies; we changed our diet and cut down on smoking.” “I know the power of digital stories to change lives. I have seen the emotion it evokes-emotion leading to change.”*

Participants described how combining digital storytelling with cancer education strengthened their practice as a community health worker. *“I talked with my patients about screening. It was my teachable moment.” “I learned to explain cancer to patient’s instead of the clinical gobbledygook, where you lose them in 2 minutes.”*

Dissemination Efforts by Course Instructor

To honor participants’ voices, experiences, and stories, the course instructor reported information back to CHWs and passed understandings forward. Participants were emailed throughout this learning journey to share ideas and invite feedback. Cancer education and digital storytelling highlights were shared in the Alaska CHA/P Certification Board newsletter and presented at the annual Alaska CHA/P conference.

Conclusions

Evaluation data from this project revealed that combining digital storytelling with cancer education for Alaska’s community health workers was feasible, culturally relevant, and enhanced learning. Participants expressed enthusiasm over learning how to use computer-based technology

to create and tell a personal story. Digital stories covered many aspects along the spectrum of cancer prevention and control including prevention, screening, early diagnosis, grief and loss, palliative and end-of-life care. Participants expressed feelings of healing and renewal as a result of developing, discussing, and sharing their stories with their colleagues. Additionally, community health workers shared ways the course encouraged them to improve their own health behavior, nurtured health activities for their families, and strengthened the ways they provided patient care. Digital storytelling, as reported by participants, was a useful health messaging tool that increased participants' confidence to discuss and share cancer information with family, friends, and other community members.

Implications for Practice

We found no information in the literature describing the feasibility and effectiveness of including digital storytelling in a cancer education course. The impact of the course is far-reaching among Alaska Native people, as digital storytelling brings the power of the media into the voices of the community members to expand cancer knowledge and empower behavior change. In the words of participants: "*One of the main things - is that the product is coming from the community - the voices and faces and stories of the people in our own communities - so it's more powerful - has more of an impact.*" "*Community members lend their natural storytelling abilities to help educate others.*" "*Our stories come from the heart.*"

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