2016

Promoting Culturally Respectful Cancer Education Through Digital Storytelling

Melany Cueva  
*Alaska Native Tribal Health Consortium*

Regina Kuhnley  
*Alaska Native Tribal Health Consortium*

Anne Lanier  
*Alaska Native Tribal Health Consortium*

Mark Dignan  
*University of Kentucky*, mbdign2@uky.edu

Laura Revels  
*Alaska Native Tribal Health Consortium*

See next page for additional authors

Follow this and additional works at: [https://uknowledge.uky.edu/internalmedicine_facpub](https://uknowledge.uky.edu/internalmedicine_facpub)

Part of the Public Health Education and Promotion Commons

Right click to open a feedback form in a new tab to let us know how this document benefits you.

Repository Citation  
Cueva, Melany; Kuhnley, Regina; Lanier, Anne; Dignan, Mark; Revels, Laura; Schoenberg, Nancy E.; and Cueva, Katie, "Promoting Culturally Respectful Cancer Education Through Digital Storytelling" (2016). *Internal Medicine Faculty Publications*. 100.  
[https://uknowledge.uky.edu/internalmedicine_facpub/100](https://uknowledge.uky.edu/internalmedicine_facpub/100)

This Article is brought to you for free and open access by the Internal Medicine at UKnowledge. It has been accepted for inclusion in Internal Medicine Faculty Publications by an authorized administrator of UKnowledge. For more information, please contact UKnowledge@lsv.uky.edu.
Promoting Culturally Respectful Cancer Education Through Digital Storytelling

Digital Object Identifier (DOI)
https://doi.org/10.18357/ijih111201616013

Notes/Citation Information
Published in International Journal of Indigenous Heath, v. 11, issue 1, p. 34-49.

Copyright © 2016 Melany Cueva, Regina Kuhnley, Anne Lanier, Mark Dignan, Laura Revels, Nancy E. Schoenberg, Katie Cueva

This work is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License.

Authors
Melany Cueva, Regina Kuhnley, Anne Lanier, Mark Dignan, Laura Revels, Nancy E. Schoenberg, and Katie Cueva

This article is available at UKnowledge: https://uknowledge.uky.edu/internalmedicine_facpub/100
Promoting Culturally Respectful Cancer Education Through Digital Storytelling

Abstract
Cancer is the leading cause of mortality among Alaska Native people. Over half of Alaska Native people live in rural communities where specially trained community members called Community Health Aides/Practitioners (CHA/Ps) provide health care. In response to CHA/Ps’ expressed desire to learn more about cancer, four 5-day cancer education and digital storytelling courses were provided in 2014. Throughout each course, participants explored cancer information, reflected on their personal experiences, and envisioned how they might apply their knowledge within their communities. Each course participant also created a personal and authentic digital story, a methodology increasingly embraced by Indigenous communities as a way to combine storytelling traditions with modern technology to promote both individual and community health. Opportunities to learn of CHA/Ps’ experiences with cancer and digital storytelling included a 3-page end-of-course written evaluation, a weekly story-showing log kept for 4 weeks post-course, a group teleconference held 1–2 weeks post-course, and a survey administered 6 months post-course. Participants described digital storytelling as a culturally respectful way to support cancer awareness and education. Participants described the process of creating digital stories as supporting knowledge acquisition, encouraging personal reflection, and sparking a desire to engage in cancer risk reduction activities for themselves and with their families and patients. As a result of creating a personalized digital story, CHA/Ps reported feeling differently about cancer, noting an increase in cancer knowledge and comfort to talk about cancer with clients and family. Indigenous digital stories have potential for broad use as a culturally appropriate health messaging tool.

Keywords
Alaska Native, community health workers, cancer education, digital storytelling, storytelling, health education, public health, health communication, Indigenous methods

Authors
Melany Cueva, RN, EDD. Alaska Native Tribal Health Consortium, Community Health Aide Program, 4000 Ambassador Dr., Anchorage, AK, 99508, USA. mcueva@anthc.org. (907) 729-2441.
Regina Kuhnley, RN, CNM, MEd. Alaska Native Tribal Health Consortium, Community Health Aide Program, Anchorage, AK, USA.
Anne Lanier, MD, MPH. Alaska Native Tribal Health Consortium, Anchorage, AK, USA.
Promoting Culturally Respectful Cancer Education Through Digital Storytelling • Melany Cueva, Regina Kuhnley, Anne Lanier, Mark Dignan, Laura Revels, Nancy E. Schoenberg, Katie Cueva

Mark Dignan, PhD, MPH. Department of Internal Medicine, University of Kentucky College of Medicine, Lexington, KY, USA.
Laura Revels, BA. Senior program manager, Alaska Native Tribal Health Consortium, Clinical & Research Services, Anchorage, AK.
Nancy E. Schoenberg, PhD, Marion Pearsall professor of Behavioral Science, 125 Medical Behavioral Science Building, University of Kentucky, Lexington, KY.
Katie Cueva, MAT, MPH. Institute of Social and Economic Research, University of Alaska Anchorage, Anchorage, AK.

Acknowledgements

Thank you to Alaska’s Community Health Aides, Community Health Practitioners, and other community health workers who generously shared their experience with creating and showing cancer-related digital stories.

The Alaska Native Tribal Health Consortium received support from the National Cancer Institute of the National Institutes of Health under award no. R21CA163163 in September 2013. The award funded research to increase understanding of digital storytelling as a culturally respectful and meaningful way for Alaska’s village-based Community Health Aides and Community Health Practitioners (CHA/Ps) to create and share cancer prevention and screening messages with Alaska’s communities. Co-funding for this 2-year award was provided by the Office of Behavioral and Social Sciences and from the Office of Disease Prevention. Research reported in this publication is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Introduction

Alaska is the largest state in the United States, one-fifth the size of the total landmass of the contiguous 48 states (State of Alaska, 2015). Alaska Native and American Indian people represent 229 federally recognized tribes in Alaska and account for approximately 19% of the state population (Bureau of Indian Affairs, 2016; U.S. Census Bureau, 2010-2014 American Community Survey). Over half of Alaska Native people live in 178 small, rural communities (U.S. Census Bureau, 2010 Census). Geographic remoteness significantly affects the ability of Alaska Native people to access the full spectrum of cancer care: education, prevention services, early detection, diagnosis, treatment, support services, and palliative and end-of-life care. Because Alaska communities have a small population, even a single person diagnosed with cancer can impact the community.

As recently as the 1950s, cancer was considered a rare disease among Alaska Native men and women (Lanier, Holck, Kelly, Smith, & McEvoy, 2001). By the 1990s cancer had surpassed heart disease to become the leading cause of mortality among Alaska Native people and remains so today (Kelly, Schade, Starkey, Ashokkumar, & Lanier, 2012). The four most frequently diagnosed cancers among Alaska Native people are colorectal, lung, breast, and prostate (Kelly
et al., 2012). Engaging in cancer risk reduction behaviors (American Institute for Cancer Research, 2015) and having recommended screening exams (U.S. Preventive Services Task Force, 2015) may reduce the burden of the most commonly diagnosed cancers among Alaska Native people.

There are 178 communities located throughout Alaska that are accessible year round only by air transportation. Communities are geographically separated from regional hospitals by immense areas of tundra, water, glaciers, and mountains. Specially trained community members called Community Health Aides and Community Health Practitioners (CHA/Ps) provide health care in Alaska’s rural communities (Golnick et al., 2012). As clinical health care providers, CHA/Ps are required to have continuing education and frequently request cancer information.1 During the 15 weeks of intensive CHA/P basic medical training, only 2 hours are devoted to cancer information (Community Health Aide Program, 2015).

To address this need for education and cancer information, story was identified by CHA/Ps as a preferred way of learning (Cueva, Kuhnley, Lanier & Dignan, 2007). Story as both form and method crosses cultural divides (Kovach, 2009), as realized by CHA/Ps who provide health care for community members from the 229 federally recognized tribes in Alaska. The tradition of storytelling is part of all Alaska Native cultures. Stories have been used to tell life lessons and pass on cultural values (Mayo & Natives of Alaska, 2002). Kovach (2009), an Indigenous educator and researcher, highlights the use of story as an Indigenous methodology; stories are a vessel for passing along teachings, medicines, and practices that can assist members of the collective. Jo-Ann Archibald (2001) reflects upon how stories capture our attention and ask us to think deeply and to reflect upon our actions and reactions, a process that Archibald calls “story work.”

Digital storytelling is an innovative health messaging tool that provides a creative and engaging way for CHA/Ps to tell their stories and pass them on. It is portable and accessible, and it can incorporate web technologies and social media. Grounded in empowerment theory (Perkins & Zimmerman, 1995), digital storytelling combines a person’s recorded voice with their choice of pictures, music, and transitions to bring the power of the media into the voices and hands of community health workers. Paulo Freire (2003), a Brazilian education theorist, advocated for empowering education that includes learners’ thought and speech as the basis for social transformation. Since its inception in the early 1990s (Lambert, 2009), digital storytelling has gained momentum as an education (Matthews, 2014; Robin & McNeil, 2012) and health promotion tool (Gubrium, 2009; Wexler, Gubrium, Griffin, & DiFulvio, 2013).

Digital storytelling has been embraced by Indigenous communities as a way to combine storytelling traditions with modern technology to promote both individual and community health (Gray, Oré de Boehm, Farnsworth, & Wolf, 2010). Given the role of story in Indigenous communities, digital stories can be viewed as “the latest manifestation of a long tradition that

---

1 In an unpublished survey (Cueva, 2009), 85 out of 85 Behavioral Health Aides and CHA/Ps requested cancer education, and 84 out of 85 wanted to learn more about cancer.
stretches back thousands of years” (Powell, Weems, & Owle, 2007, p. 12). Digital storytelling promotes creator control over the story’s structure and content, and consequently, digital stories created by, with, and for Indigenous communities challenge stereotypical representations of Indigenous people and provide an authentic reflection of traditional ways of knowing and being (Iseke & Moore, 2011). The creation of digital stories by Indigenous people can be beneficial both for the mental health of the storytellers, and as a culturally relevant way to empower individuals and communities towards health (Gray et al., 2010).

Throughout this 2-year project, we used a mixed-methods approach to listen to and learn from Alaska’s CHA/Ps about their experiences both creating a cancer-related digital story, and sharing their story’s cancer messages in their community and social networks. The project aim was to understand (a) how creating a cancer-related digital story affected Alaskan CHA/Ps’ cancer knowledge, attitudes, and health behaviors, and (b) how the CHA/Ps used their digital stories as health communication tools.

This research protocol was reviewed and approved by the Alaska Area Institutional Review Board and the Southcentral Foundation (SCF) Executive Committee and the SCF Board of Directors. Additionally, this manuscript was reviewed and approved by the Alaska Native Tribal Health Consortium (ANTHC) Health Research Review Committee (HRRC) on behalf of the ANTHC Board of Directors and the SCF Executive Committee and the SCF Board of Directors.

Methods

Four 5-day, in-person cancer education courses, utilizing the previously developed and evaluated “Path to Understanding Cancer” curriculum (Kuhnley & Cueva, 2011), were held in Alaska: two in Anchorage (March 3-7, 2014 and September 22-26, 2014), one in Bethel (October 13-17, 2014), and one in Nome (March 17-21, 2014). A total of 30 community health workers participated; the majority were female (26) and Alaska Native (24). Participants self-identified as Alaska Native (9), Yupik (7), Inupiaq (5), Siberian Yupik (1), Tsimshian (1), Tlingit (1), American Indian (1), Asian (1), and Caucasian (4). Participants ranged in age: 21-29 (10); 30-39 (5); 40-49 (5); 50-59 (6); 60-69 (4). The participants were from 21 different Alaska communities (see Figure 1), including 17 rural communities ranging in size from 42 to 829 people (U.S. Census Bureau, 2010 Population Finder). The majority of participants were Alaska CHA/Ps (25), and five people were employed in a variety of health occupations serving their communities (traditional healer, behavioral health aide, public health nurse, dietician, and health educator). Alaska CHA/Ps serve as rural Alaska’s primary care providers and take on similar roles as health educators and public health nurses. Consequently, we did not expect any differences in results between CHA/Ps and other community-based health roles. However, results were examined both among CHA/Ps alone and among all participants, with no substantial differences between the two groups. As a result, all results shared in this manuscript are drawn from the entire cohort of participants, allowing all voices to be heard.
Recruitment and Participants

Courses were advertised through existing Community Health Aide Program networks, including state wide email groups, newsletters, previous cancer education course participants, the Community Health Aide Association, and Community Health Aide Program leadership. Courses were provided in all three Community Health Aide Program training center locations, and training center program staff assisted with recruitment. CHA/Ps were selected for each course based upon their ability to actively participate in all course requirements, desire to learn about cancer, and support from their regional health corporation. Each class could accommodate 10 participants, and actual class sizes averaged 7.5 students. The attrition was due to a variety of factors including lack of funds to support CHA/P’s travel to attend the 5-day course, the inability for CHA/Ps to be away from their village-based clinical practice, adverse weather conditions that prevented scheduled air travel, and sudden personal, family, or community illness.
As part of an application that CHA/Ps completed before attending the course, the CHA/Ps described their experiences with cancer and how they hoped to apply knowledge gained as a result of course participation. All respondents knew at least one person who had been diagnosed with cancer, and many reported providing health care for someone with cancer. In the words of one respondent:

In my life I am surrounded by cancer survivors and stories of cancer. This course provides me the incentive to learn about cancer and to learn how to make and tell a digital story. I want to help my community to have a better understanding of cancer.

Cancer Education and Digital Storytelling Course Overview

Course objectives were as follows: providing basic cancer information, introducing digital storytelling as a tool for promoting cancer awareness and cancer knowledge, developing participants’ computer knowledge and skills to create a digital story, and assisting participants in developing a plan for showing their digital stories within their communities. The cancer education course included interactive learning that covered specific content based on course objectives. Cancer-specific content included: the causes of cancer; facts about cancer among Alaska Native people; healthy lifestyle choices to decrease cancer risk or prevent cancer; recommended screening exams to prevent cancer or detect it in early stages; cancer diagnosis and treatment; pain assessment and management; loss, grief, and end-of-life comfort care; and self-care for health care providers and caregivers.

The process of creating a personalized digital story in the cancer education course supported Alaska Native ways of knowing. The course included a story circle during which each participant shared the story they wanted to tell. Participants explored cancer information, reflected on their personal experiences, and envisioned how they might apply their knowledge to make a difference in cancer within their communities. A story circle, similar to a talking circle, may provide the first outlet for participants to acknowledge and create something positive from their experiences with cancer. Working with people to help them uncover meaning in their stories offers an opportunity for healing and hope as old stories are rewritten and new ones are envisioned (Gaydos, 2005). Stories may facilitate a personal journey of discovery by offering individuals a means of being understood, as well as helping to find meaning in their stories (Jones & Evans, 2008). Within the story circle, approaches to offer constructive suggestions for each other included “I really liked when …” and “If this were my story …”. Story scripts were refined prior to audio recording by inviting creators to consider their “I” message: why they want to tell this story; who they identify as potential viewers; and what they hope viewers will learn/feel/do after watching their story.

Previous research identified that telling a personal story, accompanied by factual information and images selected by the storyteller, represented a strongly engaging approach to digital stories (Cueva et al., 2015). Windows Movie Maker (free computer software) was used to make each person’s digital story. Participants recorded their written script (approximately 250 words) to give audible inflection to their personal story. Participants talked with and received...
verbal permission from any people in the photos they wished to include in their story. Additionally, to protect against copyright infringement, public domain images and music were used. Upon completion of their digital stories, course participants chose how and in what ways they authorized the course instructors to share their stories. Participants could choose to sign a written authorization form approved by the Alaska Native Tribal Health Consortium granting the two course instructors permission to show their story and/or post their story on the Community Health Aide Program website.

As part of the cancer education with digital storytelling course, participants were engaged in an ongoing dialogue to help the investigators learn about their experience with digital storytelling. This included a 3-page end-of-course written evaluation, a weekly log for a total of 4 weeks after the course reporting story showings, a group teleconference held 1–2 weeks post-course, and a survey administered 6 months post-course.

End-of-Course Evaluation

All 30 participants completed a 3-page written evaluation on the last day of the 5-day in-person cancer education course. Participants reported their experiences with combining cancer education and digital storytelling by completing open-ended and check-box questions.

Group Teleconference

Approximately 2 weeks post-course, CHA/Ps were invited by email to participate in a group teleconference to share how and in what ways they may have shown their stories. Participants were invited to share any challenges they had experienced in sharing their digital stories, as well as their perspective on viewers’ responses. Two teleconference dates were selected with participants at the end of the course to maximize teleconference participation.

Digital Storytelling Dissemination

Participants were each given a viewer log to track their digital story outreach. Log items included when and where the CHA/P showed their story, the number of viewers, and any challenges or reactions to the digital story. For 1 month post-course, CHA/Ps emailed a completed log to the primary course instructor at the end of each week. Each week, one name was randomly selected from those participants who completed a viewer log to receive a gift card.

Survey

A survey was administered 6 months post-course to learn CHA/Ps’ experience of digital storytelling over time. The 23-question survey included Likert scale, check-box, and open-ended questions. Contact information was available for 27 of the 30 course participants at the time of survey dissemination, and each participant with contact information was sent an email that included a link to the online survey via SurveyMonkey. To prompt individuals to complete the survey, three email reminders were sent over the course of 1 month. A total of 19 participants (70% of those contacted) completed the survey. The majority of respondents were women (17) and Alaska Native (13); age ranges were 21–29 (3), 30–39 (3), 40–49 (4), 50–59 (5), and 60–69 (3) (one respondent skipped this item). Two $50 gift certificates were given as a thank you to
two participants randomly selected from those who had chosen to provide their name and contact information for the drawing. No survey data were linked to participants’ names or contact information, and all responses were reported anonymously.

**Data Analysis**

Both quantitative and qualitative data were collected from end-of-course written evaluations, group teleconferences, digital story viewer logs, and the 6-month-post-course survey. Survey responses were summarized in SurveyMonkey, and data were exported into a password-protected Excel spreadsheet for analysis. Additional information from the end-of-course evaluations, viewer logs, and group teleconferences was also entered into a password-protected Excel spreadsheet for analysis by the project team. The project team also reviewed qualitative responses to open-ended questions from all evaluation tools for common themes. These qualitative themes were shared by email with the course participants, who affirmed the findings.

**Results**

All 30 course participants integrated information presented during the course to create their own personalized, medically accurate, 2-to-3-minute digital cancer story to share with people in their communities. Digital stories for which the project team received storyteller permission to share publicly are located on the Community Health Aide Program website (http://www.akchap.org/html/distance-learning/cancer-education/cancer-movies/digital-stories.html).

Each participant’s digital story incorporated one or more of the following components:

- ways cancer had touched their lives and/or the lives of those in their communities;
- cultural perspectives about cancer, reflecting cultural values, language, and traditions; and
- ways to promote health and wellness for cancer prevention and cancer risk reduction specifically for Alaska Native people.

In both the post-course telephone conversation and weekly written logs, CHA/Ps enthusiastically shared how they were showing their stories to family, friends, patients, and coworkers. Stories were shown on Facebook, YouTube, and other websites, and at a variety of community gatherings, tribal council meetings, health fairs, school classes, and even a regional basketball tournament. One month post-course, participants reported showing their digital stories over 57 times to more than 959 viewers.

Participants indicated that the process of creating a story provided an opportunity for them to gain insight into their own personal experience with cancer. They talked about creating digital stories as a way of “letting go” or a form of “emotional release.” The following common themes emerged from course participants on their experiences creating and sharing digital stories.
Digital Stories Are Culturally Respectful
On the post-course evaluation, all participants reported that they liked combining digital storytelling with cancer education as a culturally respectful way to support learning. All 6-month-postcourse survey respondents also checked “yes” in response to the question “Do you feel digital stories are a culturally respectful way to share health messages?” Additionally, respondents affirmed that they liked digital stories as a way to support learning and as a health messaging tool:

*Digital story is a unique way to share your own story and it is a powerful tool to promote health. Academic books don’t have “emotions.” Digital stories are about education through your own emotion.*

*Culturally, story teaching has been our way of life. Digital stories allow us to share with more people about our way. A lot of natives have a better understanding of cancer from other natives and the wording is so much easier to understand than all the medical language that providers use.*

Creating Digital Stories Enhances Learning
Participants emphasized the capacity of story to connect with people both affectively and cognitively, and they discussed how the process of creating digital stories increased knowledge acquisition and understanding.

*All the cancer education was great, but I learned the most from the other participants and their stories. People connect by story. Stories can be passed on.*

*You can watch it over and over and it still would be informative. Unlike reading a pamphlet over and over. Not everyone (myself) wants to do that. I never remember most of the information I read. A movie has pictures associated with the words said.*

Participants were asked to rate their knowledge of cancer both before and after course participation using a 5-point Likert scale, with 1 being *not knowledgeable*, 3 being *somewhat knowledgeable*, and 5 being *very knowledgeable*. Before the course, participants reported feeling less than somewhat knowledgeable (2.8; see Table 1). After the course, participants reported feeling very knowledgeable (4.2). This change reflects an average increase of 1.4 on the 5-point scale.
Table 1

Cancer Knowledge Self-Assessed Before and After Cancer Education Course

<table>
<thead>
<tr>
<th>Question</th>
<th>Number of participant responses</th>
<th>Avg. scale value</th>
</tr>
</thead>
<tbody>
<tr>
<td>BEFORE taking this cancer education course with digital storytelling, how would you rate your knowledge of cancer?</td>
<td>2 2 12 3 0</td>
<td>2.8</td>
</tr>
<tr>
<td>AFTER taking this cancer education course with digital storytelling, how would you rate your knowledge of cancer?</td>
<td>0 0 3 10 6</td>
<td>4.2</td>
</tr>
</tbody>
</table>

Detailed written responses substantiated the quantitatively reported knowledge gain:

Now after taking the class I was able to help my Dad get treatment for the skin cancers that had reoccurred on his back. I don’t feel scared of cancer now that I know something of the treatments available and that people are successfully treated.

I have a feeling I had some of the knowledge, but the course made me feel more comfortable in asking certain types of questions from doctors, and then finding a way to explain it easier to my patient. It’s also given me a boost of confidence to actually talk more about my patients’ feelings.

Before I hated the word cancer—it brought me to the worst days of my life taking care of my father at his end of life care. Now I am able to beg patients without crying and do it professionally for them to get early screening. Knowing early detection is key to beating cancer. This class taught me to look at something dark in my life and turn into a place where I can now face cancer.

Creating Digital Stories Increases Comfort Talking About Cancer

At 6 months post-course, survey respondents were asked to rate their comfort with talking about cancer both before and after the cancer education course on a 5-point Likert scale, with 1 being not comfortable, 3 being somewhat comfortable, and 5 being very comfortable. On average, respondents rated their comfort with talking about cancer a 2.3 prior to taking the course and a 3.9 as a result of course participation, as shown in Table 2. This reflects an average participant shift of 1.6 on the 5-point scale.
Table 2
Comfort With Talking About Cancer, Self-Assessed Before and After Cancer Education Course

<table>
<thead>
<tr>
<th>Question</th>
<th>Number of participant responses</th>
<th>Avg. scale value</th>
</tr>
</thead>
<tbody>
<tr>
<td>BEFORE you participated in this cancer education course, how comfortable were you with talking about cancer?</td>
<td>6 (Not comfortable) 4 7 2 0</td>
<td>2.3</td>
</tr>
<tr>
<td>Now, AFTER participating in this cancer education course, how do you rate your comfort with talking about cancer?</td>
<td>0 3 3 5 8</td>
<td>3.9</td>
</tr>
</tbody>
</table>

Additionally, respondents wrote in-depth comments describing changes in comfort talking about cancer as a result of participating in the cancer education and digital storytelling course:

*It was very emotional. I was able to release what I had bottled up. It helped me feel comfortable to talk about cancer, and help me accept it. I found the courage to speak to my patients, family, friends with my new knowledge of cancer.*

*Cancer is a big scary topic. When someone hears cancer, they automatically think that it IS their death. Patients don’t automatically think they can overcome it. But in our village, it seems as though you hear more about people dying from cancer than surviving cancer. Not an easy topic.*

*I am doing it now [talking about cancer]; the class gave me confidence.*

*Felt like talking about cancer when someone came home was taboo, and did not really know how to help now I have an idea. With our digital stories, I feel that it helps people not to be afraid to go out and get screenings done.*

*I am very pleased and able to associate comfortably with people who were previously diagnosed with cancer, whereas before it was very difficult, I did not know how to treat them ... how to associate or how to talk to them.*

Story creators also commented that, although cancer and cancer risk reduction behaviors can be difficult to talk about, a digital story can be used as a tool to begin the conversation. Participants also mentioned that digital stories could be widely distributed as health messages, potentially reducing the expenses of travel to disseminate cancer education:

*Digital storytelling reaches more people and can be replayed to affirm messages.*
Promoting Culturally Respectful Cancer Education Through Digital Storytelling • Melany Cueva, Regina Kuhnley, Anne Lanier, Mark Dignan, Laura Revels, Nancy E. Schoenberg, Katie Cueva • DOI: 10.18357/ijih111201616013

Opened up a new door for patients to talk about it [cancer] freely.

Digital Stories Inspire Behavior Change

On the end-of-course evaluation, 27 of the 30 participants reported that, as a result of creating their own digital story, they found positive ways to take care of themselves, their patients, their families, and their communities. Written responses included talking about and encouraging cancer risk reduction behaviors, such as quitting commercial tobacco use, having recommended screening exams, eating less processed food, and increasing physical activities:

While my digital story was in the process of coming together, I started to realize how cancer has really affected me and has hurt me. During class I decided to quit smoking.

Eat healthier, rest more, exercise more, quit smoking

Make mammogram appt

After completing their stories, CHA/Ps responded in writing to the following prompts: “I told this story because …” and “After watching my story, something I hope you think about …” In response to these questions, participants shared that their stories were personalized calls to action:

I come from a very small village but we have seen more than our share of cancer. I told this story because not a lot of people know about cancer or the things some go thru. After watching my story, I hope you think about getting your screenings or making an appointment to get screened.

At 6 months post-course, survey respondents reported changes in the ways they and their families took care of their health. In response to the question “As a result of creating your own digital story, do you do anything differently in the ways you take care of your health?”: nine people had received a recommended cancer screening exam, one person stopped using commercial tobacco, two people cut down on their commercial tobacco use, eight people increased their physical activity, and 11 people were eating healthier. A total of 12 survey respondents also reported family members doing something different as a result of the course, including trying to quit cigarette smoking, getting a recommended cancer screening exam, and eating healthier.

Digital Stories Are Enthusiastically Shared With Communities

At 6 months post-course, all respondents reported having shown their digital story, with the digital stories shown a combined total of over 94 times. Individual participants reported showing their story from 2 to 12 times or more, with several people writing “lots” and “many” for the number of times they’d shared their story. The number of viewers per showing ranged from four to more than 50 people, with additional written responses including “many people” and “everyone at home and work.” One respondent reported showing their digital story “maybe
at least 13 times a week. My kids love it and they’re always playing it almost every day.” Respondents reported showing their stories to family, friends, coworkers, youth, elders, patients, and community members. Participants reported showing their story in the clinic, at family gatherings, and during community presentations, as well as posting their stories on Facebook and the web. CHA/Ps reported that viewers liked their stories, recognized the importance of eating healthy diets and getting screened, and were motivated to make changes. Viewers also told their own stories about cancer and offered suggestions for future showings (e.g., TV screens in the hospitals). In the words of CHA/Ps:

*I think the most important part of the digital storytelling is the sharing with our communities after the class is over. Digital stories are very inspiring and promote healthy living. I find it easier and straight to the point and much better to get the message across to people. I’m not very good at public speaking and it speaks for me.*

*These stories are created by us—sometimes we make a big impact in people’s lives without knowing it. This allows us to take these movies home and show them to our families and people within our community. Some people don’t read too good and it helps them understand when we do the stories. It opens them up to ask questions and to understand more.*

**Limitations**

Only a small number of community health workers from throughout Alaska were able to participate in the cancer education course to create their digital story. Consequently, participants’ experiences, as reported within this paper, may not be representative of all CHA/Ps and other individuals working in community-based health. Expanding the reach of cancer education and digital storytelling to involve more individuals could strengthen both the impact of culturally specific health messaging and the potential to evaluate the effect of cancer-related digital stories in Indigenous communities. Due to the small size of Alaska communities, digital stories were most often shown to people known to the storyteller, and viewer responses may differ if there is not an established relationship with the story creator. Gaining feedback from viewers both known and unknown to the story creators could potentially elucidate the impact of personal relationships on viewers’ perceptions of the stories.

**Discussion**

Digital stories created by Alaska’s CHA/Ps were a culturally respectful way to enhance learning, increase cancer knowledge and comfort to talk about cancer, and inspire behavior change to reduce cancer risk. Additionally, CHA/Ps enthusiastically shared their digital stories as health communication tools to increase cancer awareness and promote cancer risk reduction behaviors among Alaska Native people. Digital storytelling holds promise to make a significant contribution to reducing cancer disparities in global Indigenous communities by providing a traditional, and uniquely modern, way to share authentic stories of culturally prioritized health
messages. The digital stories produced by Alaska’s CHA/Ps incorporated dynamic lived experiences of culture and health, transformed within the relational context of community.

Indigenous communities with traditions of storytelling, and a movement towards technology, may find creating and sharing their prioritized health messages in the form of digital stories a pathway to community empowerment and health transformation. Digital storytelling promotes creator control over the story’s structure and content, and consequently allows communities to incorporate both traditional ways of knowing and contemporary health priorities into their messages. Expanding CHA/Ps’ access to cancer education and digital storytelling could further enhance their community impact.

Digital storytelling was described by respondents in this study as a culturally respectful way to support cancer awareness and education, with sustained usefulness for themselves and their communities. As a result of creating a personalized digital story, CHA/Ps reported feeling differently about cancer, noting an increase in cancer knowledge and comfort to talk about cancer with clients and family. This shift was noted on the end-of-course evaluations and affirmed by respondents on the 6-month-postcourse survey. Throughout project evaluation, participants described how the process of creating a digital story supported knowledge acquisition and personal reflection, which often sparked emotional healing as well as a desire to engage in cancer risk reduction activities for themselves and with their families and patients.

With their cultural relevance, brevity, reproducibility, and flexibility, digital stories have the potential to be widely translated into diverse settings and locales, increasing their impact potential. Digital stories are relatively inexpensive to create and reproduce, increasing both ease of dissemination and adaptability for other health-related topics and populations. Indigenous digital stories have the potential to open cancer conversations and impact cancer prevention and detection behaviors to change the story of cancer among Indigenous people. This research serves as a strong foundation for future behavior intervention research using Indigenous digital stories as health communication tools to impact Indigenous health.

References


