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Co-Creating a Culturally-Responsive Distance Education Cancer Course with, and for, Alaska's Community Health Workers: Motivations from a Survey of Key Stakeholders

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Abstract

To gain input on a proposed culturally-responsive, distance-delivered cancer education course informed by Empowerment Theory and adult learning principles, Alaska's Community Health Aides/Practitioners (CHA/Ps) and CHA/P leadership were invited to take an online survey in February 2015. The proposed course will be developed as part of the "Distance Education to Engage Alaskan Community Health Aides in Cancer Control" project. The results of the survey demonstrate that respondents are both interested in taking the proposed class, and engaging in course development. The results also indicate that respondents have the technological comfort and capacity to be engaged in online learning, and have primarily positive experiences and perceptions of distance education. This survey is the beginning of the interactive development of the online cancer education course, and part of a continuing endeavor to promote wellness with, and for, Alaska's people by empowering Alaska's CHA/Ps and inspiring positive behavioral change to both prevent cancer, and support those who feel its burdens.

“I think this is a great step in the right direction for educating ourselves about cancer, how to cure it; how to manage it/live with it everyday. Quyanakpuk for making these first steps!”

Keywords

community health workers; community cancer education; online learning; culturally-respectful education; culturally-responsive education; Alaska Native; cancer prevention; empowerment theory; cancer education survey; adult cancer education

Background

Cancer is the leading cause of death among Alaska Native people. As recently as the 1950s, cancer was considered a rare disease among Alaska Native people, but became the leading cause of mortality in the 1990s [1]. Alaska Native people suffer disproportionate cancer mortality when compared with both non-Native Alaskans and U.S. Whites. In the period of 2008-2011, Alaska Native people had a cancer mortality rate approximately 34% higher than U.S. Whites and about 47% higher than non-Native Alaskans [2].

Exacerbating the problem, cancer education and access to health care are limited for most Alaska Native people. Over half of Alaska Native people live in rural communities, many of which are not on the road system, allowing for access only by modes such as boat, plane, or snow-machine. For these individuals, primary care is provided at one of 178 clinics located throughout Alaska. Community Health Aides and Community Health Practitioners (CHA/Ps) are often the sole health provider in these rural community health clinics. CHA/Ps are part of a well-established Community Health Aide Program (CHAP) developed in the 1960s. CHA/Ps operate within the guidelines of the Alaska Community Health Aide/Practitioner Manual (CHAM), which outlines assessment and treatment protocols. CHA/Ps are: selected by their communities; receive training at one of three CHAP Basic Training Centers located throughout Alaska (Anchorage, Bethel, Nome); and are required to participate in continuing education to maintain their CHA/P certification.

Encouraging prevention and early detection of cancer through risk reduction behaviors and recommended cancer screening exams are ways to decrease the cancer burden. On average, Alaska Native people have a higher prevalence of modifiable cancer risk factors than the U.S. population. In 2009, 39% of Alaska Native people vs. 18% of the U.S. population reported current smoking, 72% of Alaska Native people vs. 63% of the U.S. population reported being overweight or obese, and 86% of Alaska Native people vs. 77% of the U.S. population reported consuming less than five servings of fruits and vegetables per day [3,4]. There is room for positive change, as Alaska Native people are less likely to receive cancer screening exams than the average U.S. citizen, potentially due to a lack of access to medical care, including in-community medical providers and screening services. Only 51% of Alaska Native people age 50 or older reported having had a colonoscopy or sigmoidoscopy in 2008 (the most recent data available for Alaska), compared to 62% of the U.S. population [4,5]. In 2008, approximately 63% of Alaska Native women age 40 and over reported having had a mammogram in the past two years, compared to 76% of the U.S. population [4,5]. On

a national level, seeing a physician in the previous year was strongly associated with receiving a colorectal cancer screening [6]. CHA/Ps unique position as the health care providers in rural Alaska highlights their pivotal role in encouraging Alaskans to overcome barriers and attain recommended cancer screenings.

Due to the increasing cancer rates, and the impact of cancer within their communities, CHA/Ps have requested additional education about cancer. In response, the Community Health Aide Program cancer education project team developed and delivered in-person cancer and wellness classes throughout the last decade in Alaska's CHA/P Basic Training Centers (Anchorage, Nome, Bethel) [7,8]. Unfortunately, Alaska's geographic challenges (large distances, expensive airfare, and harsh weather patterns) restrict the amount of in-person cancer education that can be made available to CHA/Ps. However, increased internet access in rural Alaska has provided an opportunity to overcome these barriers. In response, a culturally-relevant, distance-delivered, online course is being developed to allow CHA/Ps to receive timely, medically-accurate, cancer education. The course is being developed as part of the "Distance Education to Engage Alaskan Community Health Aides in Cancer Control" project, supported by the National Cancer Institute of the National Institutes of Health under Award Number R25CA186882. Formative evaluation to gain community input needed to develop this proposed course included inviting CHA/Ps and CHA/P leadership to complete an online survey in February 2015. 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 (HRRRC) on behalf of the ANTHC Board of Directors and the SCF Executive Committee and the SCF Board of Directors.

Theoretical Framework

The cancer education course is being designed as part of an ongoing continuum of cancer prevention strategies working with, and for, CHA/Ps and their community members, and focusing on empowering individuals to change behavior and shift social norms. This body of work is grounded in adult learning principals and Empowerment Theory that is situated within a community-based participatory framework to provide culturally-respectful education that empowers individuals and inspires wellness activities. Empowerment Theory is summarized by Perkins and Zimmerman:

"Empowerment oriented interventions enhance wellness while they also aim to ameliorate problems, provide opportunities for participants to develop knowledge and skills, and engage professionals as collaborators instead of as authoritative experts." [9]

The survey described in this manuscript was developed and administered in a manner consistent with Empowerment Theory; designed to involve participants as professional collaborators from these first steps in articulating what a culturally-responsive distance-delivered cancer education course may look and feel like.

The cancer education course seeks to support CHA/Ps, their patients, and their communities, throughout their interactions with cancer as healthcare providers, patients, caregivers, and survivors. The course will include modules on reducing cancer risk - through nutrition, physical activity, tobacco cessation, and screenings - but also modules on cancer treatment, pain assessment and management, end-of-life comfort care, and loss and grief. The cancer prevention course will aim to inspire cancer preventive behaviors among CHA/Ps, their patients, and their communities, by both providing CHA/Ps with additional information about cancer, and enhancing CHA/P capacity and comfort with recommending appropriate cancer screening exams and modifiable behavior changes. Healthcare providers, such as Alaska's CHA/Ps, are a trusted resource for information about cancer, allowing CHA/Ps to play a critical role in cancer control and shifting both behavioral change and social norms around cancer prevention behaviors [10].

Methods

The survey was developed by a team of content experts, behavioral and social scientists, and evaluation specialists. The survey was designed to gain insight from potential participants in the cancer education course on both perspectives on distance-delivered cancer education, as well their capacity and comfort with technology involved in an online course. The survey included prompts on access to, and comfort with, technology (i.e. "I have daily internet and email access," "Please rate your comfort with online courses"), as well as questions on respondents' experiences with/perceptions of online learning. Questions were designed to inform the development of the course to enhance its' effectiveness. Prompts on engaging elements of a course, as well as elements that would be included in a culturally responsive distance education course were also developed to begin exploring what a "culturally-responsive" distance education course might be. The 16-item survey was administered online via eSurveysPro.

An estimated 378 CHA/Ps were practicing in Alaska as of July 2015. However, no master contact list for CHA/Ps exists, and the project team consequently reached out to CHA/Ps in a variety of ways. The project team sent out a link to the survey through the Community Health Aide Program (CHAP) Directors resource list, the CHAP Training Center Coordinators in hub communities, the University of Alaska Fairbanks CHAP Academic Liaison, the Community Health Aide Association President, and directly to CHA/Ps who had previously participated in an in-person cancer education course. All recipients were asked to forward the survey link on to additional CHA/Ps.

Respondents

A link to the 16-item survey was sent out on 1 February 2015, with input requested by 17 February. The project team closed the survey on 19 February 2015. A total of 70 individuals started the survey, and 62 completed surveys were received. Most survey respondents identified themselves as Community Health Aides/Practitioners (71%) although several respondents were Behavioral Health Aides (7%) or CHA/P Supervisors or Instructors (7%). Approximately 11% of the estimated 378 practicing CHA/Ps responded to the survey (see Table 1).

Due to the potentially selective nature of administering a survey online (when access to Internet may be limited for some CHA/Ps), particular care was taken to assess similarities and differences between the survey respondents and the CHA/P population as a whole. A similar percentage of male and female CHA/Ps, as well as Alaska Native CHA/Ps, responded to the survey as the general CHA/P population as of 13 July 2015 (personal communication). However, the survey respondents tended to be slightly younger, with 65% of respondents under age 39, as compared to 57% of the CHA/P population. Survey respondents also had a higher median level of formal education than the estimated CHA/P population [11].

Findings

The online survey began by asking respondents about their past experiences with online learning, as well as what they liked and did not like about distance education. Most respondents (71%, n=67) reported that they had some experience with online learning, with some enjoying *“that we don't have to travel away from family and community.”* Many individuals reported that online learning was convenient and flexible:

“I've taken on line courses in the past and thought it was well worth it. I worked on my own time and did my work when I had the time.”

When prompted to share their concerns with online learning, 34% (n=61) of respondents reported that they had no concerns about taking online courses. However, 24% shared that they were concerned about poor internet connectivity. Many respondents were worried about not receiving prompt answers to their questions in an asynchronous course, and approximately 35% of respondents were concerned about the lack of interaction that can happen with online learning:

“I particularly don't care for the limited interaction with peers. Often times meeting and bonding with peers is what makes learning fun and the exchange of information is key to learning.”

When asked specifically: “What are your concerns about learning about cancer in an online course?”, 49% (n=61) of respondents didn't report any concerns, while 17% of respondents volunteered that they felt developing an online cancer education course would be a good idea:

“I think this is an excellent way to present cancer education to people. Many more people can be taught and seems it would be cost saving.”

However, about 10% of individuals felt that there may not be enough emotional support for participants in an online cancer course:

“There are many people who have been or are impacted by cancer and my feeling is these folks would benefit from having verbal or physical contact with others to help with any trauma or PTSD associated with cancer.”

CHA/Ps Interested in Taking the Course and Engaging in Course Development

Approximately 84% of respondents (n=60) reported they would (47%) or might (40%) participate in the online cancer education course, estimated at 1.5 hours of class time per week for a 12 week session. The majority of respondents (75%) reported they had not participated in the in-person cancer education course developed and delivered by the project team over the last decade, demonstrating a continuing need for cancer education. Highlighting the positive reception of these previous courses, a greater percentage of respondents who had taken the in-person cancer education course were interested in taking the proposed course (60%), than those who had not previously experienced the in-person class (42%). In addition, 40% of survey respondents volunteered their contact information to review drafted asynchronous learning modules and assist with course development.

All Respondents Report Daily Access to Internet and Email

A total of 87% of respondents (n=61) reported daily access to a personal computer, while all respondents reported daily access to a computer or iPad. Almost all respondents reported being either comfortable or OK with using Microsoft Word (97%), email (98%), and online courses (92%). Most respondents indicated they were either comfortable or OK with using Microsoft PowerPoint (79%), Facebook (80%), and Social Media (67%). All respondents reported daily access to Internet and email, with 95% reporting access at work, and 52% reporting access at home.

Strategies to Enhance Learning and Create a Culturally-Responsive Online Cancer Course

Respondents were asked for their thoughts on making online learning helpful, interesting, and fun. In response, individuals named several items that could enhance online learning, including interactive activities such as quizzes or *“games as learning tools or test prep.”* Respondents also shared that visuals, like videos and pictures, could help to enhance learning:

“I am also very visual. Too much text without visual aids make my brain lose interest and become tired. Animation and watching videos helps a lot too.”

In response to a prompt on what an online course respectful of their culture would include, individuals shared that incorporating local statistics, pictures, and stories, including *“Examples from my culture that are relevant to materials and learning expectations,”* would be appropriate.

Individuals also felt that including information on traditional/alternative healing practices, and being respectful of diverse cultures would be part of a culturally-respectful online learning course:

“A mutual respect and regard for various cultures. To be sensitive to someone’s beliefs, values and their way of coping. To be concerned enough to really listen without so much input if not desired.”

Limitations

The survey was administered online through a link sent via email, which limits the survey respondents to those who both have access to the Internet and email, and feel are comfortable enough with the internet to take an online survey. Consequently, the survey results may not be representative of potential course participants who may have less comfort with, and/or access to, Internet technology. As it is unclear which members of the CHA/P community were reached by the survey, response rates are not available, however, individuals who had previously participated in the cancer course were emailed individually, and consequently a greater percentage of past participants may have been reached than those in the general CHA/P population.

Discussion

Given the challenges of communicating with all CHA/Ps interested in participating in online cancer education, steps have been taken to expand outreach efforts. In addition to survey respondents who volunteered to review drafted asynchronous learning modules and assist with course development, CHAP leadership, CHAP Supervisor Instructors, and CHA/Ps from throughout Alaska have been included in an online advisory email list to ensure statewide outreach and inclusion. Completed cancer education modules are advertised through the well-established CHAP infrastructure that includes: the CHAP website, CHA Association, CHAP Directors, CHAP newsletter, social media, and the eCHAM (electronic Community Health Aide Manual). Additionally, the end-of-module evaluation invites participants to respond to several questions to refine our outreach efforts, including how participants learned about the course and their motivations to take the course.

Conclusion

Survey results demonstrate that there is a population of individuals from the CHA/P community who are interested both in taking the proposed culturally-respectful, distance-delivered online cancer education course, and in providing feedback during course development. The results also indicate that respondents have the technological comfort and capacity to engage in online learning, and have had primarily positive experiences and perceptions of distance education. This survey is the beginning of interactively co-creating the online cancer education course, informed by Empowerment Theory and adult learning principles, that seeks to promote wellness with, and for, Alaskans by empowering Alaska's CHA/Ps and inspiring positive behavioral change among CHA/Ps, their patients, and their communities, to both reduce cancer risk and support those who face cancer.

“My comments are from me and people from my village/area. I think this is a great step in the right direction for educating ourselves about cancer, how to cure it; how to manage it/live with it everyday. Quyanakpuk³ for making these first steps!”

³“Thank you very much” in Yupik, the language of the Yup'ik people of Alaska

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Table 1

Demographic Characteristics of Both Survey Respondents and CHA/P Population

	Survey Respondents N (%)	CHA/P Survey Respondents N (%)	Total CHA/Ps ¹ N (%)
Total	62 (100%)	43 (100%)	378 (100%)
<i>Gender</i>			
Female	54 (87%)	38 (88%)	327 (87%)
Male	8 (13%)	5 (12%)	51 (13%)
<i>Ethnicity</i>			
Alaska Native	49 (79%)	37 (86%)	301 (80%)
American Indian	*	*	8 (2%)
Caucasian	16 (25%)	8 (19%)	33 (9%)
African- American / Black	*	*	*
Other	5 (8%)	*	*
<i>Age</i>			
20-29	19 (31%)	19 (44%)	111 (29%)
30-39	12 (19%)	9 (21%)	104 (28%)
40-49	14 (23%)	8 (19%)	66 (17%)
50-59	11 (18%)	7 (16%)	63 (17%)
60+	6 (10%)	*	23 (6%)
<i>Education</i> ²			
Some High School	*	*	24/402 (6%)
High School/GED	11 (18%)	9 (21%)	187/402 (47%)
Some college	31 (50%)	25 (58%)	146/402 (36%)
Associate Degree	11 (18%)	7 (16%)	30/402 (7%)
Bachelor's Degree	5 (8%)	*	12/402 (3%)
Master's Degree	*	*	*
<i>Tribal Health Region</i>			
Yukon-Kuskokwim	26 (42%)	23 (53%)	113 (30%)
Bristol Bay	13 (21%)	8 (19%)	51 (13%)
Other	23 (37%)	12 (28%)	214 (57%)

*
Number of respondents smaller than 5.

¹ All totals, except education, from the Community Health Aide Program via personal communication, 13 July 2015

² Estimates for education from a 2002 survey of 402 CHA/Ps [7]³ “Thank you very much” in Yupik, the language of the Yup’ik people of Alaska