Culturally-Relevant Strategies to Build Capacity Among Community Health Workers: Lessons From Alaska

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CULTURALLY-RELEVANT STRATEGIES TO BUILD CAPACITY AMONG COMMUNITY HEALTH WORKERS:
LESSONS FROM ALASKA

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The Harvard T.H. Chan School of Public Health

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Abstract

Context: Culturally-relevant health promotion with community health workers (CHWs) is an opportunity to reduce health inequities. This dissertation explores the development, implementation, and evaluation of CHW interventions in Alaska tailored to vulnerable populations to promote health behavior change that contributes to chronic disease.

Methods: This work was guided by the principles of Community-Based Participatory Action Research, honored Indigenous Ways of Knowing, and was grounded in Empowerment Theory. To explore a framework for culturally-relevant online education, the project team conducted: a focus group of Alaska Native education experts, key informant interviews of culturally and geographically diverse Alaska CHWs and their instructors/supervisors, a key stakeholder survey, and a literature review on distance-delivered education with Alaska Native or American Indian people. Findings informed the development of ten culturally-relevant online cancer education modules. A total of 428 end-of-module evaluation surveys were completed by 89 unique Alaska CHWs between January and December 2016. To study the implementation of a CHW intervention to support breastfeeding among Alaska WIC clients, 33 Women, Infants, and Children (WIC) staff/CHWs were interviewed, 25 WIC clients participated in five focus groups, and 129 clients completed surveys. Qualitative data was recorded, transcribed, and coded and analyzed in Atlas.ti. Quantitative data was summarized in Microsoft Excel.

Conclusions: Findings describe a framework for culturally-relevant online education that includes: collaborating with learners; delivering content in relevant ways, such as through personal stories, interactivity, and visuals; contextualizing information as relevant to learners’ unique realities; and connecting learners to build relationships. As a result of completing the
developed culturally-relevant online modules, learners reported they were empowered to share cancer information with their patients, families, friends, and communities, and to engage in personal cancer risk reduction behaviors such as eating healthier, getting cancer screenings, exercising more, and quitting tobacco. The implementation of a CHW-supported breastfeeding program reveals novel documentation and outreach strategies, including texting and online support groups. Findings provide opportunities for further research to test the proposed culturally-relevant online education framework and investigate health behavior change with CHW patients. Findings are potentially translatable to other culturally-relevant interventions with CHWs to promote health.
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The study described in the third paper was conducted with the support of the staff, clients, and Breastfeeding Peer Counselors of Alaska WIC. Erica Mitchell started the academic/WIC partnership, and Martín Escandón and Bianca Verma worked with Alaska’s Breastfeeding Peer Counselors to help develop the evaluation tools. The Harvard T.H. Chan Department of Social and Behavioral Sciences Maternal and Child Health Center and the Simmons College Faculty Development Fund provided funding for the study.
Introduction: Cultural-Relevancy and Conceptualizing the Rationale and Impact of Community Health Worker Interventions to Promote Health Behavior Change

This dissertation focuses on culturally-relevant strategies to build capacity among Community Health Workers (CHWs) to promote health behavior change, including changing personal cancer risk, disseminating cancer information, and supporting increased breastfeeding initiation and duration. This thesis focuses on community health worker interventions in Alaska, highlighting culturally-relevant strategies.

The first paper describes research to create a framework for culturally-relevant online cancer education developed with, and for, Alaska’s tribal health workers. This work informed and provided a context for the second paper, which describes evaluation results from the developed culturally-relevant online cancer education modules. Informed by Empowerment Theory, evaluation measures included intent to change personal cancer risk and disseminate cancer information. The third paper describes the implementation of a CHW intervention to support breastfeeding among Alaska Women, Infants, and Children (WIC) clients. Together, these three papers explore the development, implementation, and evaluation of CHW interventions in Alaska.

Cultural Relevancy

The work described in this thesis is rooted in Community-Based Participatory Action Research (CBPAR), which facilitates identifying and developing initiatives in ways relevant to the cultures and communities that are the focus of the work. CBPAR is characterized by a partnership between communities and academics/researchers to engage in work that focuses on locally relevant issues, builds on community strengths, and realizes social change that reduces inequities (Wallerstein et al., 2015). The CBPAR framework has guided the collaborations described in this research of researchers, organization staff, and CHWs.
Culture is acknowledged as vital to reduce health disparities, with cultural-relevancy though to increase the effectiveness of interventions (Thomas, 2004). However, the definition of culture remains somewhat elusive. Angayuqqaq Oscar Kawagley, an Alaska Native anthropologist, defines culture as “...the principles we acquire to make sense of the world around us” enabling individuals to “make artifacts to fit their world, generate behavior, and interpret their experiences” (2006). For the purposes of this research, culture will be considered as the ways of knowing and being that shape a community’s understanding and practice of health messaging and health promotion. While culture is a social characteristic, this work also acknowledges diversity within cultural groups and shared attributes across differing populations.

Formative work with the Alaska Community Health Aide/Practitioners (CHA/Ps) identified culturally-relevant ways of understanding and learning that echo Indigenous Ways of Knowing, which emphasize both relationships and affective/cognitive domains. As described by Gregory Cajete, an Indigenous educator and researcher:

“It is the affective elements——the subjective experience and observations, the communal relationships, the artistic and mythical dimensions, the ritual and ceremony, the sacred ecology, the psychological and spiritual orientations—that have characterized and formed Indigenous education since time immemorial. It is these aspects of Indigenous orientation that form a profound context for learning through exploring the multidimensional relationships between humans and their inner and outer worlds. ” (1994)

The work described in the first two papers honored Indigenous Ways of Knowing, and was co-developed with Alaska’s CHA/Ps, in accordance with principles of CBPAR.

In interventions with indigenous communities, historical trauma is a pertinent consideration. Historical trauma, which has disrupted traditional food systems and cultural practices has been linked to poor health outcomes, including contemporary disparities in cancer (Prussing, 2014). Acknowledging historical trauma and its many impacts, CBPAR theorists advocate that work with indigenous communities focus on supporting self-determination and empowerment (Chavez et al., 2010; Gutierrez & Lewis, 2012). The work conducted with indigenous communities in this thesis explicitly focused on cultural-relevancy, cultural strength, and community empowerment.
Intertwined with self-determination, empowerment is described as “the possibility for people to control their own lives,” and as a contextual, participatory process that advances social justice, and redistributes power to increase control (Rapport, 1981; Perkins & Zimmerman, 1995; Gutierrez et al., 1995). Empowerment is both a natural extension of the CBPAR approach, and a foundation of the broader CBPAR framework. Paulo Freire’s “popular education,” is a theoretical root of CBPAR, and advocates for empowering education that leads to social transformation – an idea that has been identified as an effective health education strategy (Wallerstein & Bernstein, 1988).

Empowerment-oriented approaches are designed to:

“…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.” (Perkins & Zimmerman, 1995)

Adding a framework and principles to guide these approaches, Empowerment Theory includes both empowering processes and empowering outcomes (Zimmerman, 1995). CBPAR is an approach that “exemplifies empowering processes,” including working with the community and building capacity (Zimmerman, 1995). Empowerment outcomes are a result of empowering processes, and are measures to evaluate empowerment-informed interventions (Zimmerman, 1995). While Zimmerman acknowledges that universal measures of the construct of empowerment would be inappropriate due to the diversity of populations and contexts to which the theory can be applied, he identifies three underlying components of empowerment outcomes: intrapersonal, interactional, and behavioral (Zimmerman, 1995). The intrapersonal component refers to changes in the way an individual thinks of themself, the interactional component includes changes in understanding about a given concern, and the behavioral component refers to actions taken to directly influence outcomes (Zimmerman, 1995). The work described in this thesis facilitates CHWs participation in the empowerment outcomes of taking action to directly promote, and engage in, positive health behavior change.

**Interventions with Community Health Workers**
While roles and responsibilities vary, Community Health Workers (CHWs) are often individuals recruited from within the communities they serve to provide healthcare services to their peers and community members. These services could involve medical care, social support, peer education, or care based on spiritual understandings of wellness (Simoni, 2011). Because they are often employed in situations and among populations where there are limited health resources, interventions with CHWs have the opportunity to reduce health disparities and promote health equity by improving health outcomes for these underserved populations (Viswanathan, 2009). Interventions with CHWs also have the potential to increase the effectiveness of an initiative, resulting in greater improvements in knowledge, positive health behavior change, and improved health outcomes, when compared with alternative strategies such as usual care, community interventions, or printed information (Viswanathan, 2009).

Conceptualizing the impact of CHW interventions

The impact of interventions with CHWs is conceptualized both using a social network approach and as a way to reduce potential barriers to receiving health messaging.

Social networks are the web of relationships that individuals are a part of (Heaney & Israel, 2008). These networks can be diagrammed by connecting each individual to those they are acquainted with through a web of relational ties. Individuals with many such ties, who are relatively centrally located in a network, are said to be “nodes.” CHWs are posited to be nodes in their community’s social networks because of their propensity to be “natural helpers;” individuals who are trusted by their community members as someone to turn to for advice and support (Heaney & Israel, 2008). CHWs also gain additional network ties through their role as peer health workers, enhancing CHWs’ potential to influence individuals in their communities.

Social support flows through the ties in social networks, and include services and tangible resources, emotional support, information, and constructive feedback/affirmation (Heaney & Israel, 2008). Interventions with CHWs can be seen as the intentional dissemination of social support such as health information, healthcare services such as treatment and referrals, emotional support, and
information that allows patients to evaluate their own personal health behaviors. Further, empowering
CHWs to model health behavior change is conceptualized as shifting actual, or perceived, social norms,
and disseminating those norms through social networks to promote health behavior change.

Barriers to successfully receiving health information include differences in power and a perceived
lack of empathy between the provider and receiver of health messaging. If an individual providing a
health message is perceived to have substantially more power than the individual receiving the message,
this barrier is thought to dampen engagement and social control, particularly when working with
marginalized populations (Simoni et al., 2011). Haeney & Israel hypothesize that effectively providing
support is more likely when both individuals are socially similar and the healthcare messenger is
perceived to have experienced similar stressors and situations (2008). CHW interventions draw on a
peer-to-peer model, with CHWs of a similar social background, with similar stressors and experiences, as
their community members. CHW interventions address potential barriers to effective health messaging,
making CHWs optimal individuals to empower individual and community-level health behavior change.
References


A Framework for Culturally-Relevant Online Learning: Lessons from Cancer Education with Alaska’s Tribal Health Workers

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Abstract:

Culturally-relevant health promotion strategies are an opportunity to reduce health inequities in diseases with modifiable risk factors, such as cancer. Alaska Native people bear a disproportionate cancer burden, and Alaska’s rural tribal health workers requested cancer information available online. In response, the Alaska Community Health Aide Program cancer education team sought to create a framework for culturally-relevant online cancer education to inform the development of distance-delivered education. Guided by the principles of Community-Based Participatory Action Research, and grounded in Empowerment Theory, the project team conducted: a focus group of Alaska Native education experts, key informant interviews of culturally diverse Alaska Native tribal health workers and their instructors/managers, a key stakeholder survey, and a literature review on distance-delivered education with Alaska Native or American Indian people. Findings describe a framework for culturally-relevant online education that includes: collaborating with learners; delivering content in relevant ways, such as through personal stories, interactivity, and visuals; contextualizing information as relevant to learners’ unique realities; and connecting learners to build relationships.

“we’re all in this together. All about conversations, relationships. Always learn from you/with you, together what we know and understand from the center of our experience, our ways of knowing, being, caring.”

Keywords: health promotion; health equity; community health workers; online learning; culturally-respectful; culturally-responsive; culturally-relevant; Alaska Native; cancer prevention; cancer education; empowerment theory; indigenous ways of knowing, community based participatory action research; online learning; adult education; theoretical framework
Background

Chronic diseases are the leading causes of death in the United States (CDC, 2016). Cancer and heart disease alone accounted for about half of all deaths in 2014, while about half of U.S. adults suffered from one or more chronic conditions in 2012 (CDC, 2016; Ward, Schiller & Goodman, 2014). However, physical activity, cancer screenings, tobacco use, and diet are modifiable risk factors that could alleviate suffering and early death related to chronic disease (CDC, 2016).

Ethnic minorities and poorer populations suffer chronic disease disparities, including higher incidences, worse outcomes, and a higher incidence of risk factors (Crook & Peters, 2008). Health promotion strategies tailored to minority populations are thought to be more effective, appropriate, and more likely to lead to health behavior change (IOM, 2002). This paper describes research to develop a framework for culturally-relevant online education developed with, and for, Alaska’s tribal health workers, to inform the development of distance-delivered cancer education.

Alaska Native people had a cancer mortality rate approximately 34% higher than U.S. Whites and 47% higher than non-Native Alaskans in 2008-2011 (Kelly et al., 2012). The leading cancer incidence sites among Alaska Native people were lung, colorectal, and breast; all of which have modifiable risk factors (Carmack, et al, 2015). In 2011-2013, 36.2% of Alaska Native adults reported current smoking, compared to 18.1% of white Alaskan adults and 19.4% of white U.S. adults (Alaska Native Epidemiology Center, 2015). In 2010-2012, 70% of Alaska Native adults reported being obese or overweight, compared to 65% of Alaska Whites, and 63% of the U.S. population (CDC, 2015; Alaska Native Epidemiology Center, 2016). In 2009, 15% of Alaska Native people reported eating five servings of fruits/vegetables per day, compared to 25%
of non-Native Alaskans and 23% of the U.S. population (CDC, 2015; Topol, 2011). Further, in 2008, 63% of Alaska Native women age 40 and over reported receiving a mammogram in the past two years, compared to 76% in the U.S. (CDC, 2015; Wells, 2009).

Primary medical care in rural Alaska, including promotion of diet, exercise, tobacco, and cancer screenings, is provided by Community Health Aides/Practitioners (CHA/Ps). CHA/Ps are often the sole healthcare providers in Alaska’s 178 rural communities not accessible by road. CHA/Ps work as part of the well-established Community Health Aide Program (CHAP), and operate within the guidelines of the Alaska Community Health Aide/Practitioner Manual (Alaska CHAP, 2016). CHA/Ps are selected by their communities and receive four 3-4 week training sessions. CHA/Ps finish basic training, a clinical skills preceptorship, and examination, then complete continuing education to maintain certification (Alaska CHAP, 2016). Only two of the 588.5 hours of basic training (0.3%) are dedicated to cancer (Alaska CHAP, 2016).

Due to the impact of cancer within their communities, CHA/Ps requested additional information about cancer (Cueva et al, 2012). In response, the CHAP cancer education project team taught in-person cancer and wellness courses during the last 15 years (Cueva et al, 2008). Unfortunately, Alaska’s geographic and financial challenges restrict the amount of in-person education that can be made available to CHA/Ps. Fortunately, the transition of CHAP clinics to high-speed Internet is an opportunity to engage CHA/Ps in online education.

During the last 15 years, ways of knowing that resonate with Alaska’s CHA/Ps have been incorporated into cancer education (Cueva et al, 2012). This study sought to understand how CHA/Ps ways of knowing could be interpreted online to develop a framework for culturally-relevant education that supports Alaska’s CHA/Ps to engage in personal cancer risk reduction and disseminate cancer information within their networks.
Methods

Theoretical Framework

This exploration of culturally-relevant online learning was guided by the principles of Community-Based Participatory Action Research (CBPAR) that honors Indigenous Ways of Knowing and is grounded in Empowerment Theory. CBPAR is a partnership between communities and academics/researchers that focuses on locally relevant issues, builds on community strengths, and realizes social change to reduce inequities (Wallerstein & Berstein, 2015). This framework guided the collaboration of the project team, CHA/Ps, and CHA/P supervisors and instructors. In alignment with the CBPAR principles to “promote co-learning and capacity building” and conduct work with community members in “collaborative, equitable partnerships,” the project team included collaborating community members throughout the process (Israel et al., 2003).

Ways of knowing that resonate with Alaska’s CHA/Ps, such as storytelling, humor, expressive arts, and building relationships, have previously been incorporated into in-person cancer education with Alaska’s CHA/Ps (Cueva, Kuhnley & Cueva, 2012). These understandings echo Indigenous Ways of Knowing, with affective and subjective elements, including the context of relationships, observations, and experiences (Cajete, 1994).

Empowerment theories are both a natural extension of the ongoing CBPAR with Alaska’s CHA/Ps, and a foundation of CBPAR. Paulo Freire’s Popular Education is a theoretical root of CBPAR, and advocates for empowering education that leads to social transformation – an idea identified as an effective health education strategy (Wallerstein et al., 1988). Empowerment-oriented approaches are also fundamental in working with indigenous communities. Historical
trauma has disrupted traditional food systems and cultural practices, and is linked by some indigenous researchers to contemporary cancer disparities (Prussing, 2014). Acknowledging historical trauma and its impacts, CBPAR theorists advocate that work with indigenous communities focus on self-determination and empowerment (Chávez, et al, 2010); an approach actualized by this project’s focus on cultural-relevancy and cultural strength. Intertwined with self-determination, empowerment is a contextual, participatory process that advances social justice, and redistributes power to increase control (Perkins & Zimmerman, 1995).

Empowerment-oriented approaches are designed to:

“...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.” (Perkins & Zimmerman, 1995)

Empowerment Theory is a framework that guides these approaches, and includes both empowering processes and empowering outcomes (Zimmerman, 1995). CBPAR “exemplifies empowering processes,” including working with the community and building capacity (Zimmerman, 1995). Empowerment outcomes are measures to evaluate empowerment-informed interventions, such as the developed cancer education modules (Zimmerman, 1995). CHA/Ps are uniquely situated to empower individual and community-level health behavior change due to their centrality within health and wellness networks.

**Focus Group Measures**

Participants were identified through snowball sampling as experts in education with, and for, Alaska Native people. One in-person 1-hour focus group was organized around participants’ schedules in December 2014. The focus group met at the Alaska Native Tribal Health Consortium, and project team members facilitated-participated in the discussion. Focus group
participants summarized key themes during the meeting after discussing topics including ways to support learning, cultural values and learning, cultural nuances to be aware of, and what makes training culturally respectful. A summary of notes was typed by a project team member who then shared the summary with focus group participants for affirmation.

Survey Measures

The 16-item survey was administered online via eSurveysPro in January 2015 to CHA/Ps, CHA/P supervisors and instructors, and other tribal community health workers in Alaska. The survey included questions on distance-delivered cancer education and capacity and comfort with online learning technology. A link to the survey was sent out in a variety of ways, with respondents encouraged to distribute to their contacts. The methodology of this survey has been published more extensively elsewhere (Cueva et al., 2015).

Key Informant Interview Measures

Key informants were selected to represent the geographic and cultural diversity of the approximately 378 CHA/Ps in Alaska (personal communication with Alaska CHAP, 2015). Each potential key informant was contacted initially through email, with follow-up via telephone. Individuals provided verbal consent and participated in semi-structured conversations facilitated by an interview guide developed by the CHAP cancer education project team. Topics included experiences with online education, culturally respectful online cancer education, information-sharing in their communities, and demographic information. The interviews were transcribed, coded and analyzed in Atlas.ti by the research team, with quantitative data summarized in Microsoft Excel.
Literature Review Key Words

Literature searches were conducted in March-April 2015 on JSTOR, Web of Science and Pubmed. The searches on distance-delivered education with Alaska Native or American Indian people used the keywords: education, and distance or online or internet, and Alaska Native or American Indian. After a scan of titles, relevant search results were downloaded into Mendeley. Duplicates were deleted, and additional irrelevant results were eliminated after an abstract review.

Funding and IRB Review

This work is part of “Distance Education to Engage Alaskan Community Health Aides in Cancer Control,” supported by the National Cancer Institute of the National Institutes of Health (NIH), award R25CA186882. Theoretical understandings and manuscript preparation and submission were supported by NIH grant 3R25CA057711. The content of this manuscript is solely the responsibility of the authors and does not necessarily represent the views of the NIH. 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.

Results

Focus Group Findings

Ten Alaska Native education experts were identified, and all participated in the focus group, including eight women and six Alaska Native or American Indian individuals. Participants identified culturally-respectful learning as including:
• Building relationships/interactions, including through collaboration, synchronous meetings, communication portals, etc., to express that individuals are valued for who they are, are respected for where they are at in terms of understanding, and are invited to learn.

“we’re all in this together. All about conversations, relationships. Always learn from you/with you, together what we know and understand from the center of our experience, our ways of knowing, being, caring.”

• Relevant information meaningful to learners, including connecting specific content “to larger cause, bigger picture” as well as including Alaska-specific information, stories, pictures, and statistics.

• Incorporating multiple modalities of learning, such as games, interactives, stories, etc.

• Incorporating visuals: “More pictures, less words.”

• Respecting traditional values by incorporating humor, storytelling, and honoring elders and ancestors.

Survey Findings

A total of 62 completed surveys were received, with 43 submitted by Alaska CHA/Ps, and others completed by CHA/P instructors/supervisors and other Alaska community health workers. In response to the prompt “An online course that is respectful of my culture would include…”, respondents shared the following common themes:

• Relevant and locally-specific statistics, pictures, examples, and stories, such as “examples from my culture that are relevant to materials and learning expectations.”

• Information on traditional/alternative healing practices, such as those shared by “traditional or tribal doctors.”
• Being respectful of individuals from diverse cultures, and allowing learners to share who they are in a supportive environment: “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.”

Respondents were also asked “What activities and/or format make online learning helpful, interesting and fun?” Individuals’ responses included the following common themes:

• Interactivity, such as quizzes, or “games as learning tools or test prep.”

• Visuals, including videos and pictures: “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.”

• Connecting in real-time with other individuals involved in the online learning to develop relationships through live chat or a live video chat.

Survey findings have been published more extensively elsewhere (Cueva et al., 2015).

Key Informant Interview Findings

Twenty-four individuals were selected to represent the geographic and cultural diversity of CHA/Ps in rural Alaska. Each potential key informant was contacted 3-5 times via email, and multiple times via telephone. More than twice the target number of key informants were selected, anticipating attrition. All potential key informants were positive about participating, but 12 were unable to find time for the conversation due to busy clinic schedules and/or subsistence activities. Twelve telephone interviews were conducted February-April 2015. All interviewees were female, and included four CHA/P supervisors and instructors, one CHAP program manager, and seven CHA/Ps. Respondents could choose multiple ethnicities; three identified as Caucasian and ten
identified as Alaska Native, including Yup’ik, Inupiaq, Siberian Yupik, Athabascan, Unangan, and “Alaska Native.” Respondents were from communities throughout Alaska, including the Aleutians and Pribilofs, Arctic Slope, Bristol Bay, Interior, Northwest Arctic, and Norton Sound. Due to uneven attrition, no men or respondents from southeast Alaska participated. Ages ranged from 15-64, with five under age 33, and six age 48 and older.

Common themes from discussions of what a culturally respectful online cancer education course would look like were:

- True personal stories of local individuals: “I really like the personal stories – it makes it real, it makes it personal and in their own words. So that means a lot.” Respondents also noted that hearing/seeing stories were a way to connect with other individuals, even if the online nature of the course didn’t allow for directly building relationships with others: “we’re all connected – the people taking the course are from all over Alaska and it’s good to see them.” Respondents noted that digital stories created during in-person cancer education courses helped learners understand content both cognitively and affectively and were relevant to include: “I know the digital stories – they are about our people. Those stories, they were pretty intense, but it would definitely be good to have digital stories in an online course.”

- Pictures/visuals, particularly Alaska-specific images and videos relevant to content: “The more of that the better (color and things), because if you think about it we’re really – a lot of us are visual people so we have to see and hear - so we’re visual. I think that’s very important because we have to visualize what’s being taught.” Interviewees also shared that too much text was a barrier to learning: “things don’t catch my attention and I would have to read a paragraph over and over and things just don’t stick if I have to read
so much to learn.” However, simplifying text to be “very basic and straight to the point” could help make reading more understandable.

- Learning through relationships. Either through hearing and seeing individuals tell their stories, or being part of a supportive group to “have the opportunity to share ideas more,” respondents discussed the importance of connecting with others to learn.
- Respondents shared their appreciation for being a part of the education development, and offered to continue being a source of information: “We could maybe get a few people in a room and just have a brainstorming session,” as well as mentioned that other potential learners could help by creating digital stories and providing information on what was relevant to them: “you could ask them – the people that are going to be taking the class,”
- Interactives/games were described as enhancing learning and reinforcing content: “What I kind of like is the definitions and like cross-matching and things like that. Maybe we could have cancer jeopardy. I don’t really play much games on the computer, but anything to do with trivia, I like that.”
- Acknowledging and respecting learners’ cultural differences and diversity among and between Alaska Native cultures: “Just to understand that there are differences, real differences in language and culture and tribes.” Survey respondents shared that acknowledging this diversity could be actualized as incorporating stories and examples from throughout Alaska.

Additionally, 25 survey respondents offered to be a resource to help guide the collaborative development of the proposed culturally-relevant cancer education.

Literature Review Findings
The literature review on distance-delivered education with Alaska Native or American Indian people produced a total of 59 articles. A scan of titles eliminated 42 results as irrelevant, and an additional four results as duplicates. The remaining 13 articles were exported into Mendeley and an abstract review eliminated six results as irrelevant. The resulting seven articles discussed the following topics:

- Examining differences in message board use between racial groups in an online educational program (1)
- Exploring ways of knowing among Indigenous learners (1)
- A distance-delivered educational intervention expanded to serve rural Alaskans (1)
- Distance-delivered educational interventions designed for Alaska Native or American Indian people (4)

Each of these articles is discussed below:

A small study on differences in message board postings examined equal numbers of Caucasian, African-American, and American Indian/Alaska Native participants who had enrolled in a diabetes self-management program (Case et al., 2009). The authors found that American Indian/Alaska Native participants logged in for shorter periods of time and wrote fewer action planning posts than Caucasian participants, but found no significant differences in the purposes of the posted messages or the ways individuals expressed themselves. However, American Indian/Alaska Native participants wrote significantly more about physical activity, particularly walking, than Caucasian participants (Case et al., 2009). The authors concluded that since participants used message boards in similar ways, they may be appropriate for a variety of users, but that more research would be needed to determine why American Indian/Alaska Native
participants posted less, talked more about physical activity and walking, and logged in for shorter periods of time (Case et al., 2009).

To explore ways to increase retention of Indigenous college students, Chávez, et al interviewed 50 Native American, Hispano, and Mestizo American students enrolled in online college courses about their ways of learning and knowing (Chávez, Ke, Herrera, 2012). The authors’ analyses of students’ narratives revealed constructs that facilitated learning, including; acknowledging the purpose of learning and connecting learning to the broader community and world, contextualizing learning with previous experiences and students’ unique contexts, facilitating learning in relationship with peers and supportive instructors, giving time for internal processing through asynchronous discussions, and learning a concept first through stories/examples following by narrowing to specifics.

The article on expanding an education program to Alaska found internet connectivity and navigating time zones a challenge, and emphasized the geographic isolation and unique challenges of providing education in Alaska (Locatis, 2009). While the article emphasized the importance of understanding the local context and coordinating with local individuals, the authors also specifically mentioned not tailoring program content for the Alaska students (Locatis, 2009).

Four articles discussed distance-delivered educational interventions designed with, and for, American Indian and/or Alaska Native people. Two of the articles were authored by members of the current CHAP cancer education project team, illuminating a lack of research in this area. However, themes were reinforced by the additional papers. A common theme included collaborative and community-based approaches that highlighted local relevance and building relationships, both in the development process and to reinforce learning (Cueva, Dignan, Lanier, 2014; Doorenbos, 2011; Galloway, 2007). Themes that resonated with Chávez et al., included
time for self-reflection, learning while connected to community, people, and place, and learning through examples, interactives, art, and stories (Cueva, Dignan, Lanier, 2014; Hites et al., 2012). However, even within this limited sample, differences emerged, potentially reflecting differences in the populations interventions were developed with and for; Doorenbos, et al. emphasized tribal sovereignty and governance (2011), while Cueva et al., articulated the role of traditional values, such as humor, in facilitating learning (2014).

Discussion

The descriptions of culturally-relevant online cancer education address a need to identify a framework for specific health promotion interventions that promote health equity. This multi-faceted study conducted with Alaska’s CHA/Ps reveals principles for culturally-relevant online cancer education:

- Collaborating: working with the learning community to tailor the educational intervention and understand how facets of the education are interpreted and valued by the diverse learner population.
- Content: incorporating ways of learning that resonate with learners. Findings indicate that distance learning with Alaska Native people includes content delivery through true personal stories, visuals, games, and interactivity.
- Contextualizing: connecting content to learners’ unique cultures, communities and regions, and the big picture; including by incorporating local information, artwork, pictures, stories, visuals, and relevant motivations to learn and synthesize content.
- Connecting: incorporating space for interactions and relationship building to learn with/from peers and instructors.
While few published articles present principles for culturally-relevant online learning with any population, two culturally-relevant online education strategies resonate with findings from this study. Sanchez and Gunawardena offered guidelines for distance-delivered education with Hispanic/Latino adult learners that included; engaging in collaborative activities, providing space to build relationships with other students and the instructor, allowing students to process and reflect by incorporating asynchronous message boards, and emphasizing concrete learning through experimentation/activities (1998). All these themes have been identified in this research, although the recommendation for asynchronous discussion emerged only in the reviewed literature, and could be considered a specific content delivery method relevant to a given population.

Grounded in distance learning for indigenous Australians, McLoughlin has proposed features of web-based education that promote equity (2000). McLoughlin emphasizes cultural maintenance (incorporating values, learning styles, etc.), while facilitating ownership of learning, communities of practice, and multiple perspectives that recognize diversity among learners.
McLoughlin’s work also resonates with the framework developed from this study’s findings, with potential overlap between constructs such as cultural maintenance and content. However, this framework takes culturally-relevant online learning a step further by emphasizing not just content delivery methods, but connections between learners and course development, implementation, and continual refinement of the educational initiative.

Conclusion

The presented framework for culturally-relevant online cancer education addresses a need for principles to guide targeted health education that promotes health equity. The identified framework will inform cancer education modules designed with, and for, Alaska’s CHA/Ps and may be adaptable to other populations or topic areas, particularly with the collaboration of potential learners. Further research is needed to test and refine this framework, and assess its impact on health equity and online learners. The four proposed constructs could both be tested individually and in concert with specifically designed educational interventions to better understand the impacts of education designed in accordance with these principles on online learners’ experiences.
References


Alaska Native Epidemiology Center, Division of Community Health Services, Alaska Native Tribal Health Consortium.


Culturally-Relevant Online Cancer Education Modules Empower Alaska’s Community Health Aides/Practitioners to Disseminate Cancer Information and Reduce Cancer Risk

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Abstract:

To address a desire for timely, medically-accurate cancer education in rural Alaska, ten culturally-relevant online learning modules were developed with, and for, Alaska’s Community Health Aides/Practitioners (CHA/Ps). The project was guided by the framework of Community-Based Participatory Action Research, honored Indigenous Ways of Knowing, and was informed by Empowerment Theory. A total of 428 end-of-module evaluation surveys were completed by 89 unique Alaska CHA/Ps between January and December 2016. CHA/Ps shared that as a result of completing the modules, they were empowered to share cancer information with their patients, families, friends, and communities, as well as engage in cancer risk reduction behaviors such as eating healthier, getting cancer screenings, exercising more, and quitting tobacco. CHA/Ps also reported the modules were informative and respectful of their diverse cultures. These results from end-of-module evaluation surveys suggest that the collaboratively developed, culturally-relevant, online cancer education modules have empowered CHA/Ps to reduce cancer risk and disseminate cancer information.

"brought me to tears couple of times, and I think it will help in destroying the silence that surrounds cancer"

Keywords: community health workers; online learning; culturally-respectful; culturally-responsive; culturally-relevant; Alaska Native; cancer prevention; cancer education; empowerment theory; indigenous ways of knowing; community based participatory action research; survey; adult education

Acknowledgements:

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Consortium Health Research Review Committee, and the Southcentral Foundation (SCF) Executive Committee and the SCF Board of Directors. This manuscript has been published in the Journal of Cancer Education: DOI: 10.1007/s13187-017-1217-4
Background

While cancer was considered a rare disease among Alaska Native people as recently as the 1950s, it is currently the leading cause of death [1]. Cancer mortality disproportionately impacts Alaska Native people; between 2008-2011, the Alaska Native cancer mortality rate was 34% higher than U.S. Whites, and 47% higher than non-Native Alaskans [2]. The leading causes of cancer incidence among Alaska Native people are lung, colorectal, and breast cancer; all of which have modifiable risk factors [1]. In 2011-2013, 36.2% of Alaska Native adults reported current smoking, as compared to 18.1% of white Alaska adults and 19.4% of white adults in the United States [3]. In 2010-2012, 70% of Alaska Native adults reported being obese or overweight, compared to 65% of Alaska Whites, and 63% of the U.S. population (2012) [4,5]. In 2009, 15% of Alaska Native people reported eating five servings of fruits/vegetables per day, compared to 25% of non-Native Alaskans and 23% of the U.S. population [4,6].

Alaska Native people are also less likely to receive some cancer screening exams than the average U.S. adult. In 2008, 63% of Alaska Native women age 40 and over reported receiving a mammogram in the past two years, compared to 76% in the U.S. [4,7]. However, an increasing percentage of Alaska Native people have reported receiving a colorectal cancer screening, decreasing the disparity between Alaska Native and White Alaskans from a 17-percentage point gap in 1993 to a statistically non-significant difference in 2012 [5].

For Alaska Native people in rural Alaska, primary medical care, including education about diet, tobacco, physical activity, and cancer screenings, is provided by Community Health Aides and Community Health Practitioners (CHA/Ps), who are often the sole health providers in their communities. CHA/Ps work as part of the well-established Community Health Aide Program (CHAP), which was developed in the 1960s [8]. CHA/Ps operate within the guidelines of the Alaska Community Health Aide/Practitioner Manual, which outlines assessment and treatment protocols for basic and emergency medical care. Community Health Aides (CHAs) are selected by their communities, and receive four 3-4 week basic training sessions. After successfully completing basic training, and a clinical skills
preceptorship and examination, CHAs become Community Health Practitioners (CHPs) [8]. Only two of the 588.5 hours of basic training (.3%) are dedicated to cancer [8].

In response to CHA/Ps requests for more information about cancer [9], the CHAP cancer education project team developed and delivered in-person cancer and wellness classes starting in 2001 [10]. However, Alaska’s large distances, expensive airfare, harsh weather patterns, and the recent statewide financial crisis restrict CHA/Ps ability to receive in-person education. Fortunately, increasing access to high-speed Internet in rural Alaska has provided an opportunity to engage CHA/Ps in timely, medically-accurate, culturally-relevant cancer education [11,12]. The cancer education has been designed to empower CHA/Ps to engage in cancer risk reduction behaviors, and to share learned cancer information. This manuscript describes online learners’ intentions to reduce their cancer risk and disseminate cancer information, and tests the hypothesis that these two intentions are correlated.

Methods

Theoretical Framework

The development, implementation, and evaluation of the online cancer education modules was guided by the framework of Community-Based Participatory Action Research (CBPAR), which facilitated honoring ways of knowing shared by Alaska’s CHA/Ps and measuring outcomes in alignment with Empowerment Theory. CBPAR is a partnership between communities and academics/researchers that focuses on locally relevant issues, builds on community strengths, and realizes social change to reduce inequities [14]. The CBPAR framework guided the collaboration of the project team, CHA/Ps, and CHA/P supervisors and instructors, to inform and empower CHA/Ps to address cancer disparities impacting Alaska Native people. Throughout the past 15 years, ways of knowing that resonate with CHA/Ps have been incorporated into CHA/P cancer education [15,2]. Alaska’s CHA/Ps also shared understandings that guided module development, with themes echoing Indigenous Ways of Knowing that emphasize relationships and affective domains [13]. As described by Gregory Cajete, an Indigenous educator and researcher:
“It is the affective elements—the subjective experience and observations, the communal relationships, the artistic and mythical dimensions, the ritual and ceremony, the sacred ecology, the psychological and spiritual orientations—that have characterized and formed Indigenous education since time immemorial. It is these aspects of Indigenous orientation that form a profound context for learning through exploring the multidimensional relationships between humans and their inner and outer worlds.” [16]

Working with CHA/Ps and honoring Indigenous Ways of Knowing, the educational modules were developed to include visuals, local information, storytelling, cultural teachings, imagery, and interactivity to connect affective and cognitive domains and empower learners to engage in, and promote, cancer risk reduction behaviors. For example, digital stories created by CHA/Ps that described their connection to the land through hunting and gathering were used to underscore messages on healthy diet and physical activity, while connecting learners to traditional values.

Empowerment is both a natural extension of the ongoing CBPAR with Alaska’s CHA/Ps, and a foundation of CBPAR. Paulo Freire’s Popular Education is a theoretical root of CBPAR, and advocates for empowering education that leads to social transformation – an idea that has been identified as an effective health education strategy [17]. Empowerment-oriented approaches are also fundamental in working with indigenous communities. Historical trauma has disrupted traditional food systems and cultural practices, and is linked by some indigenous researchers to contemporary cancer disparities [18]. Acknowledging historical trauma and its impacts, CBPAR theorists advocate that work with indigenous communities focus on self-determination and empowerment [19]; an approach actualized by the project’s focus on cultural-relevancy, cultural strength, and empowerment. Intertwined with self-determination, empowerment is a contextual, participatory process that advances social justice, and redistributes power to increase control [20]. Empowerment-oriented approaches are designed to:

“…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.” [20]

Empowerment Theory is a framework that guides these approaches, and includes both empowering processes and empowering outcomes [21]. CBPAR “exemplifies empowering processes,” including working with the community and building capacity [21]. Empowerment outcomes are a result
of empowering processes, and are measures to evaluate empowerment-informed interventions [21]. While Zimmerman acknowledges that universal measures of the construct of empowerment would be inappropriate due to the diversity of populations and contexts in which the theory can be applied, he identifies three underlying components of empowerment outcomes: intrapersonal (changes in the way individuals think of themselves), interactional (changes in understanding about a given concern), and behavioral (actions taken to directly influence outcomes) [21].

CHA/Ps are uniquely suited to empower individual and community-level health behavior change due to their centrality in each community’s health and wellness social network. Working with CHA/Ps is conceptualized as disseminating information and empowerment through existing social networks to promote health behavior change. This study tests the theory that empowering CHA/Ps to engage in cancer risk reduction behaviors supports them to disseminate cancer information to their patients and community members. This theoretical assumption is supported by a previous study’s findings that patients were more motivated by healthcare practitioners who engaged in healthy practices, while providers with healthy habits were more likely to discuss these behaviors with their patients [22].

**Learners**

The Director of CHAP Rural Health Services identified 379 CHA/Ps practicing in Alaska as of May 2016 via personal communication. However, no master contact list for CHA/Ps exists. The project team consequently reached out to CHA/Ps about the online cancer education modules in several ways. As each module was completed, information on the module was sent to CHA/Ps who previously participated in in-person cancer education courses, posted in the CHAP Newsletter, highlighted on the CHAP website, and sent to the CHAP Directors resource list, the CHAP Training Center Coordinators, the University of Alaska Fairbanks CHAP Academic Liaison, and the Community Health Aide Association President. All recipients were invited to share the information widely to reach additional learners. While the modules were designed with, and for, Alaska’s CHA/Ps, all modules are free and publically accessible.
Curriculum

Substantial formative work was undertaken by the CHAP cancer education project team at the Alaska Native Tribal Health Consortium, in collaboration with CHA/Ps and their supervisors and instructors, to learn how to create culturally-relevant, distance-delivered, cancer education [13]. Four common themes were identified as culturally-relevant online learning: incorporating local information, personal stories, visuals, and respect for individual learner’s cultures. The project team developed ten culturally-relevant cancer education modules: Men’s Health; Colorectal Cancer; Cancer and Our Genes; Cancer Basics; Cancer Treatment; Cancer Pain; Loss and Grief; Women’s Health, Tobacco, and Nutrition & Physical Activity. Each module was approved as Continuing Education (CE) by the CHAP certification board. CHA/Ps are required to complete CE to maintain certification.

To create each online learning module, a project team member drafted a storyboard in Microsoft Word that incorporated visuals, storytelling, interactivity, cultural teachings, and respect for diverse Alaska Native learners’ cultures. The storyboard was then reviewed by content experts, CHA/P collaborators, and members of the CHA/P community. After incorporating all edits, a project team member translated the storyboard into an online learning module using the software “Storyline.” The module was then reviewed by CHA/Ps, CHA/P instructors and directors, content experts, and the project team, with input informing changes in module design, format, and content. The finalized version was then published online. Each two-hour learning experience was designed to support CHA/Ps in their capacity as healthcare providers and community members. Consistent with the principles of CBPAR of co-learning and collaborative work [23], learners were asked about their perspectives of the modules, with iterative adjustments made to the modules in response.

Measures

Each module is available on the CHAP Distance Learning Network, where learners create an account to access the modules. After completing a module, learners are required to complete an evaluation survey before receiving Continuing Education. The evaluation survey was developed...
collaboratively by CHA/Ps and the project team to better understand learners, their perceptions of the modules, and to measure components of empowerment outcomes. The survey includes prompts on demographic information, motivations to take the module, perceptions of cultural respectfulness of the module, respondents’ likes, critiques, and suggestions, as well as respondents’ intent to share cancer information and change behavior as a result of module completion. End-of-module evaluation surveys collected through the CHAP Distance Learning Network between January and December 2016 were downloaded, then cleaned and summarized in Microsoft Excel. Contingency tables, Pearson chi-square, and odds ratios were calculated using Stata 12.1 to examine associations between intent to disseminate cancer information and intent to reduce cancer risk.

**Funding and IRB Review**

This work is part of “Distance Education to Engage Alaskan Community Health Aides in Cancer Control”, supported by the National Cancer Institute of the National Institutes of Health (NIH), award R25CA186882. Data analysis, theoretical understandings, and manuscript preparation and submission were supported by NIH grant 3R25CA057711. The content of this manuscript is solely the responsibility of the authors and does not necessarily represent the views of the NIH. This research protocol was reviewed and approved by the Alaska Area Institutional Review Board, the Alaska Native Tribal Health Consortium (ANTHC) Health Research Review Committee, and the Southcentral Foundation (SCF) Executive Committee and the SCF Board of Directors. This manuscript was reviewed and approved by ANTHC and SCF.

**Results**

**Learners**

A total of 89 unique CHA/Ps completed at least one evaluation survey in 2016, an estimated 26% of the 379 total practicing CHA/Ps. In total, 473 evaluation surveys were completed in 2016, with 90% completed by CHA/Ps (428 surveys), and 8% completed by other community health workers, healthcare
professionals, and community members. The number of learners engaging in the modules continues to rise, with about an additional 7.5 unique learners each month. About half (45%) of CHA/Ps who submit an evaluation completed 1-3 modules, and about a third (37%) completed 6 or more modules.

Demographics are summarized in Table 1:

Table 2. Demographic Characteristics of Unique CHA/P Learners and Estimated CHA/P Population

<table>
<thead>
<tr>
<th></th>
<th>Unique CHA/P Learners</th>
<th>Total CHA/P Population</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Total</td>
<td>89 (100%)</td>
<td>379 (100%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>75 (84%)</td>
<td>324 (85%)</td>
</tr>
<tr>
<td>Male</td>
<td>14 (16%)</td>
<td>55 (15%)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alaska Native</td>
<td>73 (82%)</td>
<td>303 (80%)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>15 (17%)</td>
<td>30 (8%)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (7%)</td>
<td>43 (11%)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>17 (19%)</td>
<td>101 (27%)</td>
</tr>
<tr>
<td>30-39</td>
<td>23 (26%)</td>
<td>116 (31%)</td>
</tr>
<tr>
<td>40-49</td>
<td>26 (29%)</td>
<td>71 (19%)</td>
</tr>
<tr>
<td>50-59</td>
<td>15 (17%)</td>
<td>68 (18%)</td>
</tr>
<tr>
<td>60+</td>
<td>8 (9%)</td>
<td>23 (6%)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some High School</td>
<td>*</td>
<td>24/402 (6%)</td>
</tr>
<tr>
<td>High School/GED</td>
<td>35 (39%)</td>
<td>187/402 (47%)</td>
</tr>
<tr>
<td>Some college</td>
<td>51 (57%)</td>
<td>146/402 (36%)</td>
</tr>
<tr>
<td>Associate Degree</td>
<td>20 (22%)</td>
<td>30/402 (7%)</td>
</tr>
<tr>
<td>Bachelor’s Degree</td>
<td>*</td>
<td>12/402 (3%)</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Health Aide</td>
<td>36 (40%)</td>
<td>194 (51%)</td>
</tr>
<tr>
<td>Community Health Practitioner</td>
<td>53 (60%)</td>
<td>185 (49%)</td>
</tr>
</tbody>
</table>

*Number of respondents smaller than 5. Actual number redacted to protect the identity of respondents.

Most CHA/P population estimates were provided via personal communication from the Community Health Aide Program 16 May 2016, while education information is from a previously conducted survey of 402 CHA/Ps [15]. Learner demographics are similar to the CHA/P population, although learners tended to be more middle-aged and have more formal education, potentially as a higher percentage of learners were Community Health Practitioners (CHPs), who have passed CHAP Basic
Training and are more advanced than CHAs. In addition, the module evaluations allowed learners to check multiple ethnicities, while the population estimate includes only one per CHA/P, potentially contributing to the higher percentage of learners who identify as (also) Caucasian.

**CHA/P Perspectives of Online Cancer Education Modules as Culturally-Respectful and Informative**

Write-in responses on what learners liked about the cancer education modules included that they felt the modules were informative (173 responses), liked the personal stories (64), appreciated the videos/visuals (30), and enjoyed the interactives/quizzes (18). Learner comments reinforced both the connection of affective and cognitive domains emphasized in Indigenous Ways of Knowing, and highlighted the usefulness of the online learning modules in supporting CHA/Ps to engage with the topic of cancer:

“This was a meaningful and well made learning module, as every single one of us can take tips and apply it in our lives. Also, the subject matter is sacred, has to do with honoring our loved ones and most often we are uncertain and don’t know how to approach something as important as those two things.”

“brought me to tears couple of times, and I think it will help in destroying the silence that surrounds cancer.”

Learner comments also underscored understandings of the power of story in cancer education with Alaska’s CHA/Ps [15]: “The digital stories added human nature to all facts presented.” CHA/Ps shared how the modules were useful as tools to share cancer prevention messages with their patients, serving as “useful testimonies I think they will help me counsel patients about screening for cancer.”

In response to a question on how to make the cancer education modules better, CHA/Ps indicated on most surveys (75%) that they had no suggestions and/or felt the modules were good as is: “This is great. Good mix of stories, facts and illustrations.” When asked about module challenges, CHA/Ps said they had no challenges on 61% of surveys, and commented on technical challenges, primarily internet connectivity, on 21% of surveys.

On 100% of the end-of-module surveys, CHA/Ps shared that they’d learned what they’d hoped to learn from the modules. On almost all surveys (97%), CHA/Ps reported that the modules were respectful
of them and their cultures, with positive sentiments affirmed in write-in comments: “beautiful thought of and well designed to reflect what Native people can relate to.” CHA/Ps were also asked to comment on their motivations for engaging in the module, with results summarized in Table 2:

Table 2. CHA/Ps’ Motivations to Take Culturally-Relevant Cancer Education Modules

<table>
<thead>
<tr>
<th>Survey completed by each unique CHA/P</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All</td>
</tr>
<tr>
<td>Total</td>
<td>428</td>
</tr>
<tr>
<td>(100%)</td>
<td>(100%)</td>
</tr>
</tbody>
</table>

Why did you choose to take this online learning module?

<table>
<thead>
<tr>
<th></th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needed continuing education</td>
<td>364 (85%)</td>
</tr>
<tr>
<td>Wanted to learn more about cancer</td>
<td>120 (28%)</td>
</tr>
<tr>
<td>Looked interesting</td>
<td>91 (21%)</td>
</tr>
</tbody>
</table>

1Individuals may check more than one box, consequently totals do not add up to 100%

The majority of respondents indicated they had engaged in the online learning for Continuing Education (table 2). The relatively small percentage of respondents who indicated they went through their first module because they wanted to know more about cancer (34%) indicates that the cancer education has reached CHA/Ps who may not have otherwise sought out information about cancer. In addition, the desire for Continuing Education was a motivator for CHA/Ps to complete modules, despite numerous CHA/P Continuing Education opportunities.

CHA/Ps Empowered to Disseminate Cancer Information and Reduce Cancer Risk

All surveyed CHA/Ps reported they intended to use information learned during the cancer education modules, including with their patients (84% of completed surveys), families (60%), friends (53%), and communities (64%). Write-in comments shared how the focus on local, relevant content connected with CHA/Ps and supported them to disseminate cancer information in their communities:

“I saw a relative from my region that had cancer and I didn't know about it. I knew she was sick but I didn't know it was cancer. It brought all the information close to home and made me want to share more with family and friends.”

As a result of completing a cancer education module, 94% of unique CHA/P learners planned to change at least one of their own health behaviors within six months. Table 3 tests the theoretical
assumption that intent to reduce personal cancer risk, and intent to disseminate cancer information to patients, family, friends, and communities, are correlated:

Table 3. CHA/Ps Intent to Reduce Cancer Risk in Response to Culturally-Relevant Online Cancer Education is Highly Correlated with Intent to Disseminate Cancer Information

<table>
<thead>
<tr>
<th>CHA/P Surveys N (%)</th>
<th>Surveys intending to disseminate information to:</th>
<th>Odds Ratio (Lower Confidence Interval, Upper Confidence Interval)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patients</td>
<td>Family</td>
</tr>
<tr>
<td>Total N (%)</td>
<td>428 (100%)</td>
<td>360 (84%)</td>
</tr>
<tr>
<td>Will the information in this module make a difference in the ways you take care of yourself? Within the next six months, I plan to:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not make any changes</td>
<td>86 (20%)</td>
<td>0.88</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(0.46, 1.68)</td>
</tr>
<tr>
<td>Get information about having a recommended screening exam</td>
<td>111 (26%)</td>
<td>1.06</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(0.98, 1.97)</td>
</tr>
<tr>
<td>Schedule a recommended screening exam</td>
<td>84 (20%)</td>
<td>4.16</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(1.45, 11.95)**</td>
</tr>
<tr>
<td>Have a recommended screening exam</td>
<td>98 (23%)</td>
<td>2.76</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(1.21, 6.32)**</td>
</tr>
<tr>
<td>Stop using tobacco</td>
<td>59 (14%)</td>
<td>12.14</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(1.61, 91.59)**</td>
</tr>
<tr>
<td>Cut down on my tobacco use</td>
<td>84 (20%)</td>
<td>0.90</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(0.46, 1.75)</td>
</tr>
<tr>
<td>Increase my physical activity</td>
<td>201 (47%)</td>
<td>2.30</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(1.29, 4.12)**</td>
</tr>
<tr>
<td>Eat healthier</td>
<td>178 (42%)</td>
<td>1.71</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(0.97, 3.03)</td>
</tr>
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*p<.05  **p<.01  ***p<.001  - = odds ratio cannot be calculated due to a small cell size
1Individuals may check more than one box, consequently totals do not add up to 100%
2These odds ratios compare the odds of learners intending to disseminate information to a specific group on an evaluation survey if a given behavior is intended, with the odds of a learner intending to disseminate information to the group if that behavior is not intended on a survey
A statistically significant association was found between intent to reduce cancer risk and intent to disseminate cancer information for almost all variables. For example, if a learner checked on a survey that they intended to increase their physical activity within the next six months as a result of the module, they had about 4.7 times the odds of indicating they also intended to share cancer information with their family (confidence interval of 3 to 7.5), when compared with surveys where learners did not intend to increase their physical activity. Further, not intending to reduce cancer risk was statistically significantly associated with not intending to disseminate cancer information for almost all variables. On almost all surveys (84%), CHA/Ps reported they would share learned cancer information with their patients, which may explain the few non-significant findings.

**Discussion**

The culturally-relevant online cancer education modules have empowered CHA/P learners to intend to share cancer information with their patients, families, friends, or communities, and intend to reduce their cancer risk, including by getting a cancer screening, eating healthier, being more physically active, and quitting tobacco. Further, a statistically significant correlation was found between planned behavior change and intent to share cancer information, substantiating the theoretical assumption that empowering CHA/Ps to reduce their cancer risk is an important factor in inspiring learners to disseminate cancer information.

Aspects of the culturally-relevant cancer education may be adaptable to interventions specific to other cultural contexts, including; working with the target population to develop and refine the initiative; incorporating visuals, data, language, and content related to the geography, values, and beliefs of the population; and including personal stories of individuals from the community that share content in ways that are meaningful and may resonate with the target group. However, the language, beliefs, values, geography, etc. will vary widely depending on the population the material is developed with, and for.

The learning modules have been developed in an online format to address a need for remote access to medically-accurate cancer information. Portions of CHA/P Basic Training have been moved
online, which has increased CHA/Ps’ familiarity with online learning. All CHA/Ps have Internet access in their clinics, however, CHA/Ps may not have home Internet access. Only 33% of rural Alaskans were estimated to have high-speed Internet access in December 2014 [11], which could prevent some CHA/Ps from participating in the modules if their employers aren’t supportive of CHA/Ps engaging in cancer education during the work day. In addition, an estimated 26% of all CHA/Ps completed an evaluation survey in 2016. While additional CHA/Ps continue to engage in the learning modules, the number of CHA/P learners is small relative to the population of Alaska’s CHA/Ps. Formative work to assemble a master contact list of all CHA/P emails could have increased the reach of the modules and been an effective strategy to increase engagement. If there are systematic differences between CHA/P learners and CHA/Ps who have not participated in the modules, the results may be biased.

This manuscript describes results from completed evaluation surveys that assess learners’ likes, critiques, suggestions, and intent to reduce cancer risk and disseminate cancer information. However, intent does not always materialize in lived behavioral change, and additional research would be needed to assess the impact of the online cancer education modules on realized cancer risk reduction behaviors. However, in theoretical models such as the Theory of Reasoned Action, the Theory of Planned Behavior, and the Integrated Behavioral Model, intention is seen as the most important determinant of behavior [24]. Testing the Theory of Reasoned Action on cancer risk reduction behavior, Montaño and Taplin found a .50 correlation between behavioral intention and mammography screening [25], despite the lack of a culturally-relevant intervention to empower either high levels of intent or behavior.

Conclusion

The online learning modules address a lack of culturally-relevant cancer education available to CHA/Ps, and allow CHA/Ps to receive timely, medically-accurate information remotely. Results document that all CHA/P learners were empowered to share cancer information, and almost all (94%) were motivated to engage in behavioral change to reduce their own cancer risk. The collaboratively developed, culturally-relevant, online learning modules are a well-received strategy to provide rural
Alaska’s primary care providers with cancer education that has inspired behavioral change and knowledge dissemination through the existing networks of CHA/P learners. The evaluation results indicate that CHA/P learners have appreciated the content, format, and feel of the modules, and have been empowered to change both their own behavior, and share cancer information with their patients, families, friends, and communities. In the words of learners:

“It [the cancer education online learning module] brought to light some issues for cancer patients that I otherwise would have had no idea about. It didn’t just brush on a subject and leave you wanting more answers, any question I had was quickly answered in the module. The information was concise and put together in a way that was very fluid and made sense to be in that order.”

“I am happy to have learned this, and that I am able to share it now”
References


Innovative Strengths and Challenges of the Alaska WIC Breastfeeding Peer Counselor Program: A Qualitative Study of Program Implementation

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Abstract

Objective: This study explored the implementation of a Breastfeeding Peer Counselor (BFPC) program at Alaska Women, Infants, and Children (WIC).

Design: Qualitative study utilizing focus groups, surveys, and interviews.

Setting: Research conducted at all five Alaska WIC BFPC sites.

Participants: Participants were 33 interviewed WIC staff/BFPCs, 25 clients in five focus groups, and 129 surveyed clients.

Phenomenon of Interest: Perceived strengths/challenges of Alaska WIC BFPC program implementation, and supports/barriers of clients’ breastfeeding.

Analysis: Transcripts analyzed in Atlas.ti using a general inductive approach to identify emergent themes. Survey data summarized in Microsoft Excel.

Results: Clients identified BFPCs’ knowledge, supportiveness, accessibility, support group facilitation, and post-birth assistance as program strengths. BFPCs and staff described BFPCs’ accessibility, knowledge, relatability, and capacity to reach out to clients through texting and online support groups as positive elements, with challenges including limited in-person contact with clients, hours, and funding, and confusion about the BFPC role. BFPCs and staff described unique documentation strategies, strengths and gaps in training on breastfeeding, and perceived supports/barriers of WIC clients’ breastfeeding.

Conclusions and Implications: The implementation of a BFPC program in Alaska WIC reveals novel documentation and outreach strategies, including texting/online support groups, findings potentially translatable to other peer counseling programs.

(200 words)

Keywords: Community health workers; Breastfeeding; Women, Infants, and Children; WIC; Alaska; Support groups; Texting; social media; internet
INTRODUCTION

Breastfeeding improves the health of both infants and mothers, with benefits including decreased risk of childhood obesity and diabetes, reduced risk of maternal diabetes and breast cancer, and increased mother/child bonding. Breastfeeding peer counselors (BFPCs) are usually recruited and hired from within the populations they serve, and are paid paraprofessionals that support clients to initiate and continue breastfeeding. Numerous randomized controlled trials (RCTs) have documented that interventions with BFPCs increased breastfeeding initiation, duration, exclusivity, positive mother and child outcomes, and are perceived positively by both mothers and BFPCs. After documenting BFPCs’ effectiveness in RCTs, the next stage of research is that of implementation science; the study of strategies used to deploy evidence-based interventions in a specific context.

The Women, Infants, and Children (WIC) program is uniquely positioned to support and promote breastfeeding among U.S. individuals vulnerable to low breastfeeding rates, as WIC serves a population challenged by disparities in breastfeeding initiation and duration. A key component of WIC breastfeeding promotion and support are BFPCs employed to “increase breastfeeding initiation and duration rates for WIC participants, as well as to increase community support for WIC participants who breastfeed.” This paper explores the strategies used to implement a BFPC program among Alaska WIC clients, program strengths and challenges, and perceived barriers and supports of clients’ breastfeeding. In 2015, 5 out of 13 WIC sites in Alaska employed BFPCs. These 5 sites included Alaska’s urban centers of Anchorage and Fairbanks, the rural communities of Bethel, Juneau, and Homer, as well as remote clients served through clinics in those rural communities. Alaska WIC BFPCs work with a broad spectrum of clients, including military families stationed on bases, Alaska Native mothers in rural areas, fundamentalist religious communities, and diverse urban populations. Supporting WIC clients in Alaska
requires innovation, with 13 Alaska WIC sites serving over 21,000 clients scattered throughout a geographic area more than twice the size of Texas.\textsuperscript{9} Alaska WIC clients are diverse, with 1/3 of infants identified as Alaska Native or American Indian.\textsuperscript{9} While Alaska WIC clients have lower breastfeeding initiation and duration rates than general national averages (36.6% of Alaska WIC infants breastfed through 6 months in 2014, compared with 51.8% of all infants nation-wide\textsuperscript{8,9,11}), Alaska WIC breastfeeding rates are well above the national WIC average; in 2014, 36.6%/\textsuperscript{8} of Alaska WIC infants breastfed for at least 6 months, compared with 27.0% of WIC clients nationwide.\textsuperscript{9}

Alaska WIC began a BFPC program in 2005 with new sites added to the program through 2011. The Alaska WIC BFPC program recruits and hires BFPCs who have successfully breastfed for at least six months and are among the WIC client population. Alaska WIC BFPCs are employed for approximately 10 hours/week outside normal business hours to encourage breastfeeding initiation and duration among a caseload of WIC clients. Given the gradual roll-out of the Alaska WIC BFPC program and few program sites, power was limited to determine a statistically significant change in breastfeeding rates before and after BFPC program implementation. Consequently, this qualitative study has been conducted to explore the challenges encountered, and innovative strategies used by Alaska’s BFPCs to support breastfeeding.

**METHODS**

**Context**

A study of the implementation of the Alaska WIC BFPC program was identified as a research priority by Alaska WIC staff. Utilizing a Community-Based Participatory Action Research (CBPAR) framework, the study was co-designed by academic researchers and WIC staff, including co-development of the research design, interview and focus group guides, and consultation on interpretation of findings. BFPCs were consulted prior to the evaluation to provide feedback on the research design, evaluation needs, and interview guides. The study design explores constructs of Social Cognitive Theory, which posits that human behaviors are the product of personal, behavioral and environmental influences.\textsuperscript{12} Study questions inquire about perceptions of WIC clients’ self-efficacy, collective efficacy, self-regulation, and
the tools/resources/environments that make breastfeeding easier or more challenging. To examine program implementation challenges and strengths, we drew data from multiple perspectives, including WIC clients, BFPC counselors, and WIC staff members. The study was reviewed, and found exempt, by the Harvard T.H. Chan Institutional Review Board (IRB), the Simmons College IRB, and the University of Alaska Anchorage IRB.

**Focus Groups**

Alaska WIC BFPCs identified clients as potential focus group participants in 4 of the 5 Alaska WIC BFPC sites, with a total of 5 focus groups completed. In alignment with a CBPAR approach, Alaska WIC BFPCs identified client identification and recruitment strategies that best fit their site and client population. Five focus groups were conducted at 4 BFPC sites in June and July 2015 (2 focus groups were conducted at 1 site), involving a total of 25 Alaska WIC BFPC clients. In 2 focus groups, BFPCs invited the researcher to recruit individuals and conduct focus groups from clients who attended breastfeeding support groups on a given day (resulting in a group of 3 and another of 6). BFPCs identified potential clients for 2 focus groups, who the researcher then recruited and followed up with (3 and 11 participants), and 1 site advertised the focus group to all current BFPC clients (2 participants). Focus group discussions were conducted by a trained researcher not affiliated with Alaska WIC and facilitated by a written focus group guide co-created by WIC staff and researchers. Verbal consent was attained from all participants and no incentives were provided. Topics included interactions with the BFPC program, strengths and challenges of the program, and barriers and supports to clients’ breastfeeding. Common themes for each focus group were summarized by participants and recorded by the focus group facilitator.

**In-Depth Interviews**

In-depth interviews of WIC BFPCs and other WIC staff were conducted at each of the 5 WIC BFPC sites by a trained researcher not affiliated with Alaska WIC. All BFPCs and WIC staff who interacted with clients about breastfeeding were identified by the BFPC coordinator at each site, and
invited by the researcher to participate in interviews. Verbal consent was obtained from all interviewees, and no incentives were provided. The 30-60 minute interviews were facilitated by a semi-structured interview guide that included prompts on daily activities, training, referral and documentation, perceptions of supports and barriers to clients’ breastfeeding, and perceived BFPC program strengths and challenges. Interviews were audio recorded and transcribed by the researcher and a professional transcription service.

Client Surveys

Alaska WIC staff mailed surveys to 100 randomly selected BFPC clients at each of 3 participating sites. The surveys were developed by WIC staff and included 4 check-box and 6 open-ended questions about clients’ breastfeeding status, reasons for continuing/stoping breastfeeding, perceptions of the BFPC program, and suggestions for improving the program. Collected surveys were entered into Microsoft Excel by WIC staff, with de-identified data provided for inclusion in this study.

Data Analysis

With participant oral consent, interviews were recorded, transcribed, coded in Atlas.ti for thematic and structural components, and analyzed for common and co-occurring themes by trained academic researchers not affiliated with Alaska WIC using a general inductive approach. The inductive approach is a simple, systematic set of procedures that condenses text data collected from an evaluation into a summary format. Findings stem directly from the raw data and evaluation questions, and not from a priori expectations or theoretical models. To alleviate potential bias in transcript interpretation, a randomly selected 13% of the transcripts were coded independently by 2 researchers to develop a codebook and establish consistency of inter-rater application of the codebook through consensus. One researcher then applied the developed codebook to the remaining transcripts. Focus group common themes for each group were summarized by participants and recorded by the focus group facilitator. Quantitative survey results were summarized in Microsoft Excel.
RESULTS

Common themes are presented below by research methodology, and include client interactions with BFPCs through texting and online support groups, perceived breastfeeding supports and barriers, perceptions of the BFPC program, documentation challenges and strategies, and staff perspectives on training.

Focus Groups

A BFPC was present at a single focus group, although no differences in emergent themes were found. A total of 7 clients reported participating in the BFPC program for 0-5 months, 10 for 6-11 months, 6 for over 6 months, and 2 declined to answer. About 16 clients worked with only 1 BFPC, while the remaining worked with 2 or more.

Client interactions with BFPCs. The majority of focus group participants at sites with an online support group reported learning about the BFPC program from that group. The majority of participants at other sites learned about the program from WIC staff members. At some sites, participants expressed confusion about the BFPC program and its’ connection to WIC: “I’m not sure, they just called me and checked up every month. Might have been through WIC?”

Participants at sites with online support groups interacted with BFPCs via the online support group and phone, while participants at other sites talked with their BFPCs in person, via text, and during regularly scheduled WIC visits. Most participants shared that there were more interactions just after birth to support early challenges: “For the first month – 3x week. Then 1-2/week until we felt comfortable with his weight gain – that was the main concern for me seeking consultation because he had difficult time gaining weight the first month.”
Perceived breastfeeding supports and barriers. Participants shared that receiving “support, encouragement, reassurance that I’m doing the right thing” from their BFPCs, advice on proper latch, and access to a breast pump, were contributors to their breastfeeding success. Identified facilitators of breastfeeding for Alaskan women included ease of breastfeeding (particularly when compared to formula), awareness and knowledge of the health benefits of breastfeeding, challenges with formula feeding (including cost and fear of negative impacts on their babies), support to pump at work, and a supportive partner/community/family, including the BFPC-facilitated support groups that modeled breastfeeding as a social norm: “Supported by community/family. Seeing the ladies here today and knowing that they all breastfeed and knowing that I have this group of ladies to turn to if I have a question.” Focus group participants identified barriers to breastfeeding that included (from most to least common): fear of not producing enough milk, discomfort with breastfeeding in public, limited social support, lack of support for breastfeeding problems, alcohol use, and pain/discomfort.

Perceptions of the BFPC program. To stay engaged in the BFPC program, respondents talked about the importance of being a part of a supportive community, a personal relationship to the BFPCs, and having access to a breast pump. Participants identified the strengths of the BFPC program as BFPCs’ knowledge, supportiveness, and accessibility: “To have someone there 24/7 - to have for support. I don’t know where I’d go without the program, I probably wouldn’t still be breastfeeding. I was struggling, but I was given a tremendous amount of help.” Clients at sites with online support groups spoke highly of the interactions they had through these webpages: “having a team of cheerleaders through Facebook is really nice.”

Most respondents reported that the BFPC program had no challenges/barriers. However, some participants were interested in being contacted more frequently by their BFPC, having a way to access breastfeeding information outside of normal business hours, such as a hotline or a website, being part of a support group for mothers, and receiving more support immediately after giving birth: “More support when baby first come out in hospital – like during the hospital stay. More one-on-one teaching in the hospital. Like how to teach baby to latch on.”
In-Depth Interviews with WIC Staff and Breastfeeding Peer Counselors

In June and July 2015, 33 individuals (97% female) were interviewed at all 5 Alaska WIC BFPC sites. A total of 14 individuals identified as current or former BFPCs, and 27 reported they had other WIC roles (lactation consultants, competent professional authorities, coordinators, etc.), including 17 individuals who had multiple previous/current WIC roles. All BFPCs and staff identified as interacting with clients about breastfeeding participated in an interview. Interviewees had a median of 5 years of work experience at WIC, ranging from new hires with less than a month at WIC to individuals with 20 years of employment. Common themes are summarized in the following domains; BFPC training, documentation strategies, perceived support of WIC clients’ breastfeeding, barriers to WIC clients’ breastfeeding, strengths of the BFPC program, and challenges of the BFPC program.

Perspectives on training. Most Alaska WIC BFPCs described receiving training online through the Loving Support curriculum, which is provided by the Food and Nutrition Service to train WIC peer counselors and their managers.7 BFPCs shared positive views of the training, but noted a gap in guidance on BFPC day-to-day duties: I feel like the training really helped me as far as educating me on breastfeeding and things like that, but as far as what my job entailed and what my job duties were, that kind of took me a while to get used to that and figure it out on my own.” This lack of guidance was substantiated by WIC staff who shared that the BFPCs, due to time constraints, were “…kind of out there on their own and nobody’s interacting with them, and I think they’d have better retention, better staff retention if we could connect with them better.” BFPCs identified personal experiences with WIC and breastfeeding, as well as mentorship/shadowing, as most helpful in preparing them for their work. “the shadowing was really good, because it’s one thing to read about it and another to see it in action.”

About half of interviewed WIC staff who were not BFPCs talked about participating in breastfeeding-related trainings, while about half described receiving little formal training about breastfeeding. Most interviewed non-BFPC WIC staff shared that they’d received little formal training on
the BFPC program, although several felt that their training on, and experience with, breastfeeding helped them to better understand the program. These interviewees also described mentorship and shadowing as positive training opportunities, even when conducted remotely.

**Documentation strategies.** Most of the interviewed WIC staff and BFPCs described using both the Alaska WIC software system and supplementing that system with unique documentation strategies. Interviewees described creative strategies to track client contacts and referrals, including typing notes on each client, storing text conversations on WIC cell phones, or developing paper forms that could be passed between individuals: “...it’s hard to do a follow-up when you don’t know who’s referred to the Breastfeeding Peer Counselor... So I had set up a system in the basket, where these referrals go, there’s a clipboard where we can write down who’s been referred, so we have a list of who’s been referred so we can follow-up.” These supplemental tracking systems were described by some interviewees as more efficient than the Alaska WIC software system: “...once I give her [another WIC staff] the person’s name, I give her the entirety of all my interactions with that one person, all together in one note, one email, so that she doesn’t have to go into SPIRIT [the software system] and click into every single deal, come out, go back in... that’s a tedious thing”

**Perceived support of WIC clients’ breastfeeding.** The most frequently shared common themes on breastfeeding support were: social support, including that provided by family and peer counselors; education, including WIC education; and online support groups. Interviewees noted that social support, whether it be the client’s friends, parents, husband/boyfriend, or BFPCs, were determinants of breastfeeding success, with education informing clients and changing perspectives on breastfeeding.

Several interviewees described the positive potential of online support groups, including individuals at 2 Alaska WIC BFPC sites who maintained Facebook pages for their clients:

“The Facebook page is incredible. It’s a really something that on any given day there are probably 3 or 5-6 posts by women who have a question or have a story or a success that they individually want to share, and the immediate feedback they get from their peers about that
breastfeeding thing is awesome…. I don’t want to say it’s our biggest success, but it is pretty amazing how successful it is."

Many interviewees shared a desire to create an in-person or online support group. However, staff described challenges in getting clients to attend in-person support groups, potentially due to issues with transportation or childcare. Interviewees were positive about online support groups, although some were concerned that the pages addressed clients’ needs outside of the WIC clinic:

“We also have a Facebook page that we started… and it’s awesome because it’s peer support… So many moms have connected with other moms and they’ve kept breastfeeding because they feel that support… but on the flip side a lot of moms feel like they’re getting support from there and they don’t want us to call or text them or they just don’t even come back in as WIC clients.”

The inaccuracy of WIC clients who successfully breastfed not returning to WIC for their status to be recorded was identified: “for me it’s a heartbreak in the numbers… They never come in to recertify because we’ve done such a good job counseling them on breastfeeding.”

Perceived barriers to WIC clients’ breastfeeding. Common themes included clients’ families, the first couple of weeks after birth, and social norms. Interviewees noted that a new mother’s “support system is also… their challenge,” as “I think the family influences are pretty big. Something as simple as their mom saying – well, I didn’t have enough breastmilk for you, you’re not going to be able to breastfeed – that can just set her up for failure right there.” The first few weeks after birth were identified as a particularly challenging time: “Definitely that first two weeks that could be uncomfortable/painful, where there could be cracking/bleeding, a poor latch.” Suggested strategies to increase support postpartum included developing a relationship between BFPCs and pregnant moms before birth, and connecting with hospitals and birthing centers so BFPCs could know when a baby was born and provide breastfeeding support. This was seen as important to long-term breastfeeding success, as “if they can make it past the 2-3 week period, I think they see that this is going to work for me, I’m going to accomplish this goal.” Additionally, social norms were seen as a barrier to breastfeeding, including a social taboo around breastfeeding publicly, and a normalization of formula feeding.
**Perceived strengths of the BFPC program.** Common themes included that BFPCs were accessible, knowledgeable, relatable, and could reach out to clients through texting. Interviewees described BFPC accessibility: “I think that’s the major strength, there’s help right there. It’s the middle of the night when you fall apart... You can’t call anyone, but breastfeeding peer counselors are there.” Interviewees described BFPCs as knowledgeable of both breastfeeding and community resources, in part because of their training and personal experiences that allowed them to be relatable: “They’ve had some of the problems, they’ve had mastitis, they’ve had breast issues. Some of them have had latch issues. So they have firsthand knowledge of how it is and what it takes and they can relate to the clients on that level.” BFPCs’ are required to have been previous WIC clients who successfully breastfed, and their experiences were described as enhancing their connection, and ability to provide social support, to clients:

“They’re good at relating and I think that is a strength that the mom can call up and just vent to somebody and have that open relationship they’re more apt to ask for help with breastfeeding and not feel so closed off. I think that the peer counseling program is very good at the model they’ve set up of not shutting anybody out, very open to different family dynamics. WIC sees so many different clients that you kind of have to be open to where somebody’s at”

Individuals shared that texting allowed clients to have conversations in a modality comfortable to them, that both didn’t disturb sleeping children or family members, and could be done while a baby was awake and crying and a mother needed immediate assistance.

**Perceived challenges of the BFPC program.** Common themes included limited; hours, funding, and in-person contact with clients, confusion about the BFPC role, and barriers to accessing documentation software. Interviewees noted the difficulties of creating and maintaining relationships with clients with limited opportunities for in-person contact: “it was just a cold call, like how’s it going. I’m the breastfeeding peer counselor and you’ve never seen my face.” Interviewees described how this could lead to poor BFPC retention and effectiveness:

“It could be discouraging for women to cold-call people that they don’t know. It’s part of the position to call and check in on Moms. A lot of women respond negatively to that – they don’t know you, they hang up on you, they don’t want to be bothered. If they have a breastfeeding concern, they’ll come in to the WIC office or go to see the IBCLC at the clinic.”
This created challenges both for BFPCs attempting to reach out to clients, and for other WIC staff that found themselves fielding calls and questions from clients that might have been better served by a BFPC, potentially as clients were “more comfortable with somebody that they see on a regular basis.” This problem was exacerbated by remote clients served via distance by WIC staff and BFPCs: “We use phones for those appointments, but it’s clearly not as strong as in-person especially if you’re trying to show them some techniques to improve with their breast feeding, it’s kind of tough to do even on a video.”

BFPCs talked about the tension of limited funding/hours and a desire to serve clients: “I definitely think we need more hours to do the job right…I don’t want to not pick up the phone at night because I’m at my 12 1/2 hours, y’know, I’m just not going to do that, so then I just don’t write that time down, and I can’t really afford to work for free either.”

Interviewees shared that clients perceived BFPCs as having more advanced capacity than their scope of practice, and that the distinction between BFPCs and other WIC roles was blurred by numerous staff with overlapping positions. The BFPC role was described as challenging to define, as:

“even though it’s a ‘peer counseling’ program, because it comes from an institution, a clinic, we’re still seen as professionals. So that’s kind of a weird thing, it’s like, they want us to be professionals, they train us to be, in a way, but they also want us to just be one of the moms…”

This tension was particularly pronounced for more experienced BFPCs who had confidence in their experiences and skills, but were limited by their scope of practice. As a BFPC shared:

“…a good example would be a tongue tie…So then the peer counselor down here who’s not supposed to know anything about that. Even if we know gobs about it we can’t really talk about it because that’s technically outside our scope. So it’s like it could be very much affecting that client’s breast feeding relationship and we know, like in my mind I’m thinking a simple -they go get the tongue clipped and voila, things are better, but it’s like I can’t sit there and say this is what you should do.”

Limited BFPC access to the WIC documentation software was also noted as a barrier, with staff explaining that BFPCs didn’t “have the access in SPIRIT [the documentation software] that we have, so to me that’s kind of a barrier, that she has to rely on us to do things.” Since the majority of BFPC work took place at BFPCs’ homes, the need to travel to the office to document client contacts was a challenge, especially given limited transportation and child care. While some BFPCs did not have Internet access at
home, others shared that: “I’d love to be able to have the access to SPIRIT [the documentation software] at home so I can just enter it.”

Client Surveys

WIC staff provided surveys of 129 randomly selected WIC clients collected April-May 2015 from 3 sites (serving approximately 4,000 WIC infants). Response rates ranged from 32% to 56% at each site. Two additional Alaska WIC BFPC sites did not submit client surveys for inclusion in this study. The majority of surveyed clients (73%) reported that BFPCs helped them breastfeed for a longer period of time, with write-in comments expressing that BFPCs were “…doing an amazing job, I never thought that I'd get this far! I gave myself a 6-week goal and with all your encouragement, help and support I'm almost to 8 months! Thank you so much.” Clients shared overwhelmingly positive descriptions of their interactions with BFPCs, attributing BFPCs “support, encouragement, reassurance that I’m doing the right thing” as determinants of their breastfeeding success: “Thank you for the help! We would have gave up on breastfeeding if it wasn't for the help and support!” Clients wrote that their BFPCs were supportive: “she was one of the very few that supported me on my breastfeeding journey,” and relatable: “Having a BFPC felt more personal, easier to bring up my concerns or questions.”

The majority of respondents who no longer breastfed shared that they’d stopped because of concerns about milk supply and transitions back to work. To support this transition, clients discussed a desire for a support group “more geared towards working mothers. It would be nice to talk to other breastfeeding working moms.” Another support strategy was the use of breast pumps, with approximately 64% of surveyed clients reporting using an electric breast pump, and most indicating the pump helped them continue breastfeeding after returning to work or school.

Interactions between survey respondents and BFPCs varied widely, with about 40% of respondents at a site indicating they’d seen a BFPC just once, while about half at another site sharing they’d worked with a BFPC 3 or more times, potentially due to differences in BFPC staffing and outreach strategies. While in theory each WIC client would have contact primarily with 1 BFPC, limited BFPC
hours and BFPC turn-over could result in clients seeing more than 1 counselor. When asked specifically “Do you have any suggestions for improving our peer counseling program?” the majority of respondents indicated the program was good as is, and wrote in comments about the benefits they’d received: “peer counseling has been great and so helpful! This program is wonderful and I hope it continues. I will continue to use it as long as I am breastfeeding and it exists.” Clients saw texting as a convenient way to reach BFPCs, and positively described online support groups: “the Facebook group has been an invaluable support system - well monitored and positive.”

**DISCUSSION**

Clients and staff identified BFPCs’ knowledge, accessibility, supportiveness, and accessibility as program strengths. Clients additionally described the value of breastfeeding support groups and post-birth assistance while BFPCs and staff noted BFPCs’ capacity to reach out to clients through texting and online support groups as positive elements. BFPC and staff identified program challenges, and described BFPC implementation innovations.

The outreach strategies of online support groups and texting were described as supporting WIC clients’ breastfeeding in all study research modalities (focus groups, surveys, interviews). These strategies differ from previously documented WIC BFPC outreach, with a nationally representative study finding that WIC BFPCs predominantly reached clients via telephone and in-person at WIC offices. Online support groups and texting are also novel as documented approaches to supporting breastfeeding outside of the context of WIC, with relatively few references found in the peer-reviewed literature. However, the articles that do refer to these strategies indicate their use among breastfeeding mothers, and describe their potential to provide positive support. A 2013 study examining the types of support provided through online breastfeeding discussion boards found that informational support was most frequently requested/received, while emotion-focused support was also requested and provided. Breastfeeding mothers are also documented as seeking out online social support in a 2015 study on breastfeeding after gestational diabetes. Further, breastfeeding mothers in Australia, Ireland, and Sweden were documented
as seeking “informal online support” for accessible encouragement and emotional support, with Irish mothers ranking informal online support as the second most important contribution to their breastfeeding success.\textsuperscript{16} However, a systematic review of health related virtual communities/electronic support groups found that “no robust evidence exists” on the health impacts of peer-to-peer online communities.\textsuperscript{17} In addition, a 2016 meta-analysis of e-technologies to improve breastfeeding outcomes posited that text messaging could communicate health information, provide psychological benefits, and impact breastfeeding behavior among hard-to-reach populations due to its efficiency and low cost, with the authors finding that one-way text messaging interventions improved exclusive breastfeeding duration.\textsuperscript{18}

Previous studies have found that WIC BFPC programs vary in the types of training offered to BFPCs, how BFPCs contact clients, and even in the information documented about BFPC clients,\textsuperscript{10,19,20} echoing challenges identified in the Alaska WIC BFPC program. Confusion about the Alaska WIC BFPC role, and differences in documentation strategies, are also opportunities to enhance BFPC training and share documentation best practices between sites for using both the software and supplemental systems. Mentorship/shadowing has been identified as a commonly used training strategy in WIC BFPC programs,\textsuperscript{10} and could also reduce confusion around the BFPC role.

Threats to internal validity include differences in recruitment strategies for focus groups at each site, which may have resulted in participants who do not share views representative of the general population of Alaska WIC BFPC clients. BFPCs recruiting clients may have also made clients reluctant to not participate. It’s unclear if there are systematic differences between the client survey respondents and those who chose not to participate, which may also threaten internal validity. In addition, study participants may have been reluctant to speak poorly of their employer/provider and could have refrained from providing more critical feedback, particularly if surveys were given directly to WIC staff, or a focus group conversation included WIC BFPCs. External validity may be threatened by the time-specific nature of the research. While all BFPCs and identified WIC employees consented to an interview, this census sample is representative of a single time-point that may not be translatable to other groups of staff. In addition, as only a randomly selected 13% of interviews were coded independently by 2 researchers to
develop the qualitative codebook and establish consistency of inter-rater application of the codebook, there may have been inconsistencies in application of the codebook in other interviews that could result in bias.

**IMPLICATIONS FOR RESEARCH AND PRACTICE**

Texting and online focus groups are innovative strategies used by Alaska WIC BFPCs to support clients’ breastfeeding success. Findings from this study may inform programmatic change at Alaska WIC to better meet staff and client needs and contribute unique outreach strategies to other peer counseling programs. Other organizations utilizing social media or texting will also need to ensure HIPAA compliance. While the emerging literature is promising, the effectiveness of BFPC, or other peer counselor, facilitated online support groups/texting is an area for future research. This qualitative study on the implementation of a BFPC program with Alaska WIC documents that the evidence-based initiative of BFPC has been adapted to fit the context of Alaska WIC, with BFPCs and WIC staff innovating unique implementation strategies. Other studies on the implementation of evidence-based programs may find similar user innovations that adapt the program to a specific context.
References


