Original Research

Developing the Native People for Cancer Control Telehealth Network

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Abstract

Objective: We aimed to develop a telehealth network to deliver postdiagnosis cancer care clinical services and education to American Indian and Alaska Native patients, their families, and their healthcare providers. We also sought to identify the challenges and opportunities of implementing such a telehealth-based application for this rural and underserved population. **Materials and Methods:** We followed a participatory formative evaluation approach to engage all stakeholders in the telehealth network design and implementation. This approach allowed us to identify and address technical and infrastructure barriers, lack of previous experience with telehealth, and political, legal, and historical challenges. **Results:** Between September 2006 and August 2009, nine tribal clinics in Washington and 26 clinical sites in Alaska had participated in the telehealth network activities. Network programming included cancer education presentations, case conferences, and cancer survivor support groups. Twenty-seven cancer education presentations were held, with a total provider attendance of 369. Forty-four case conferences were held, with a total of 129 cases discussed. In total, 513 patient encounters took place. Keys to success included gaining provider and community acceptance, working

closely with respected tribal members, understanding tribal sovereignty and governance, and working in partnership with cultural liaisons. **Conclusion:** The telehealth network exceeded expectations in terms of the number of participating sites and the number of patients served. Following a participatory formative evaluation approach contributed to the success of this telehealth network and demonstrated the importance of community involvement in all stages of telehealth system design and implementation.

Key words: distance learning, telehealth, telemedicine

Introduction

Telehealth has the potential to increase access to healthcare and health information among underserved and rural segments of our society. Some of the earliest telehealth projects involved American Indians (AIs).^{1,2} In the past decade, a growing number of telehealth applications have targeted such rural and underserved populations, although few have focused on AI and Alaska Native (AN) populations or highlighted teleoncology.

Cancer is now the second leading cause of death for AI/ANs over 45 years of age,^{3–5} and AI/ANs have the worst cancer survival of any U.S. racial/ethnic group.⁶ However, specialized cancer care and information is often not available to tribal communities. Availability of congressionally determined monies from the Indian Health Service (IHS) Contract Health Services determines patients' access to specialty care. AI/AN patients can wait on priority lists for months and then are provided travel and accommodations for themselves alone to a preselected medical center.⁷ Likewise, the Alaska Tribal Health System, which provides cradle-to-grave comprehensive care for eligible beneficiaries, has only two oncologists to care for the estimated 150,000 ANs living in Alaska. These factors introduce potentially huge barriers in terms of location, transportation, and time to obtain cancer care.⁸

Another consideration in providing healthcare to AI/ANs is incorporating culturally competent services that encompass their belief systems regarding health and healing. To address the needs of remote, rural AI/AN populations in our region, we initiated the Native People for Cancer Control Telehealth Network (NPCCTN). Our overarching aim was to use telehealth to provide and improve access to culturally sensitive and relevant postdiagnosis cancer care services for remote and rural AI/AN communities in Washington and Alaska. In this article, we will present the unique opportunities and challenges that we encountered in implementing this project. Our experience is recounted within the broader context of the historical, legal, financial, and cultural factors that influence the relationship between AI/AN communities and academic institutions

seeking to pursue health-related projects and offer care to these communities.

Methods

The NPCCTN used telehealth technologies to provide cancer-related educational sessions, consultative services to providers, and support groups for cancer patients, their families, and their health-care providers throughout Washington and Alaska. We followed a participatory formative evaluation approach, defined as a learning process for the end-users that helps them reach their desired goals.⁹ In this process, all stakeholders participate substantively in identifying the issues needing evaluation and formulating actions taken as a result of the evaluation findings.¹⁰ We engaged our partners in all stages of implementing and evaluating the network to ensure that the NPCCTN addressed the needs of their stakeholders. The approach was actuated primarily through twice-yearly strategic planning meetings with stakeholders and weekly team meetings that included Alaska-based team members.

The adoption of an information technology (IT)-based application or design of a new system for rural and/or underserved settings requires identifying specific IT needs, understanding the existing infrastructure, and developing a strategy to increase technology acceptance and diffusion. Empirical evidence indicates that health-care organizational readiness for new technology is crucial to successful innovation.¹¹ To ascertain readiness of the participating sites, we involved our partners in an ongoing process of identifying needs of, and challenges to, implementing the telehealth technologies.

Despite this approach, the NPCCTN encountered challenges in establishing the network, including (1) technical issues, (2) provider, patient, and community acceptance, (3) cultural issues, and (4) engaging our partner organizations. In terms of technical challenges, a major key to our success was assessing technical readiness and technical training. Our first priority was to establish operational and technical connections with our partner networks in Alaska and to equip our rural western Washington tribal sites with video teleconferencing systems. We devoted considerable time to successfully linking our video teleconferencing bridge with the Alaska-based network bridges and to test the connection to these bridges as well as the connection to the remote sites on these Alaska-based networks. In Washington, simple matters of geography and winter weather conditions led to technical installation delays. In one case, it took 4 months to bring in a new T1 line because new wires had to be trenched into a site located > 150 miles from Seattle. The technical staff at the University of Washington (UW), at tribal local sites, and at IHS clinics also collaborated closely to resolve interoperability and firewall issues. Six of the seven participating sites connected through existing private networks, or their IHS network, and in two cases, on-site technical staff spent up to 3 weeks opening up firewalls to allow the connection with the UW. Other technical challenges included deciding on the appropriate type of equipment to purchase while keeping in mind the technical support available at each site and determining the optimal location of the equipment for the planned educational programs and clinical services.

To ensure a successful technical implementation, we followed the guidelines for human factors considerations in telehealth provided by the American Telehealth Association Human Factors Special Interest Group,¹² including reflection of human factor issues in decisions about selection of vendors, use of observations and interviews to understand our user profiles, their needs, and their expectations, and the creation of user scenarios that informed training and quality control initiatives.

Some of our Washington sites and providers had little to no experience using telehealth. Therefore, the NPCCTN Project Director, Project Manager, and Technical Director worked closely with a local coordinator at each site to educate and train providers on use of the equipment, primarily through in-person visits. Training both the technical staff and the providers, with a goal of comfort and confidence with the technology, was crucial to the success of the project. Direct patient care required extra time to explain the videoconferencing system to patients and to address questions or concerns, especially with regard to privacy and confidentiality. Because trust between patient and provider may be difficult to achieve when using telehealth technologies, the local coordinator or healthcare provider was given responsibility for logistics and continued outreach at remote sites and was present at the beginning of each visit. The local coordinators also educated their communities regarding telehealth, conducted outreach efforts, and endeavored to integrate telehealth activities into clinic workflow patterns.

We also strove to understand and respect the historical, legal, political, and cultural issues unique to these federally recognized AI/AN tribes. Events in the history of AIs with the U.S. government, education, and healthcare institutions have led to a general mistrust of government, educational institutions, healthcare institutions, and research endeavors.¹³⁻¹⁷ Multiple layers of permission from clinic and tribal entities must typically be obtained prior to engaging in this type of project, with final approval in the form of a Tribal Resolution and/or Memorandum of Understanding signed by the Tribal Council.¹⁸ Understanding mistrust, tribal sovereignty, and governance and proceeding through the appropriate channels were paramount to the success of implementing the NPCCTN. In addition, because the NPCCTN worked with geographically and culturally distinct clinicians, patients, and systems of care, university-based NPCCTN providers and staff completed cultural competence training.¹⁹ The provision of culturally congruent healthcare facilitates strong relationships between academic and tribal providers and AI/AN people.²⁰

A related issue was engaging our tribal clinics. Owing in part to staffing issues, individual clinics had fluctuating levels of interest and engagement. The high turnover of providers in the IHS and the shortage of healthcare professionals working in AI/AN communities make healthcare access and provision for AI/ANs a challenging issue.²¹ Busy tribal clinic providers, staff, and administrators had other priorities, which affected their engagement in new projects.

To improve engagement in Washington and Alaska, the NPCCTN staff frequently communicated with sites through e-mail, telephone, and in-person visits and participated formally and informally in numerous cancer-related activities such as local conferences and

health and wellness fairs. These outreach efforts were directed at tribal councils, elders, other community members, as well as healthcare providers. We also created and disseminated a poster incorporating art donated by an AI artist that introduced and defined telehealth for our target communities. A large part of our success was due to the efforts of Seattle and Anchorage-based AI/AN team members and the local coordinators, all of whom who served in part as outreach and cultural liaisons for the project.

Results

As of August 2009, nine tribal clinics in Washington and 26 clinical sites in Alaska had participated in the NPCCTN activities. This included six tribes in Washington that had passed a tribal resolution and signed a memorandum of understanding, plus three other tribes in Washington that had joined the NPCCTN activities as a result of word-of-mouth and informal outreach. Additionally, we extended invitations to participate in the NPCCTN programs to two tribes in Montana, to the Northwest Indian College, and to sites on the UW Telehealth Network given that these sites are primarily rural critical access hospitals that serve Native Americans within their region. As of August 31, 2009, both tribes in Montana, five Northwest Indian College sites (four in Washington and one in Idaho), and nine of the UW Telehealth Network hospitals had participated in the NPCCTN activities. In Alaska, the NPCCTN linked with the Alaska Federal Health Care Access Network, the telehealth network of the Alaska Native Tribal Health Consortium that serves over 250 sites throughout Alaska. However, shortly after we began delivering the NPCCTN programs, three additional Alaska-based networks—the Alaska Rural Telehealth Network, the Eastern Aleutian Tribes Corporation, and the SouthEast Alaska Regional Health Consortium—requested access to the NPCCTN programs. A total of 26 individual sites in Alaska have participated in the NPCCTN activities.

The NPCCTN activities included a Providers Education Series; access to Continuing Medical Education, Continuing Nursing Education, and Continuing Educational series in oncology, medicine, lab medicine, pediatric medicine, cardiology, psychiatry, pediatric nursing, and grand rounds, an Emergency Medical Service training

series, and an Emergency Department nurse training series; case conferences regarding psychological issues, pain management, and end-of-life issues; and a Cancer 101 educational series and support group meetings for cancer survivors.²²

Between August 2007 and December 2008, the NPCCTN's health-care providers' education series offered sessions on survivorship care, end-of-life issues, cancer care for children, pharmacological pain management interventions, and reviews of specific types of cancer. From February 2008 through September 2009, the NPCCTN offered a monthly support group meeting for cancer survivors that incorporated an educational presentation on a variety of issues related to survivorship, a question and answer session, and an opportunity for cancer survivors across the region to interact via video teleconference.²³

Beginning in September 2008, the NPCCTN also began offering a monthly case conference series focused on cancer pain management issues, psychological issues, and end-of-life issues. The NPCCTN was also able to respond to sites' requests for teledermatology services by providing a monthly skin cancer and dermatology case conference series. Also in response to site requests, the NPCCTN provided direct telepsychiatry services to patients at two tribal sites starting in February 2009. *Table 1* provides specific information about each of these series, with regard to the number of attendees or cases, participating sites, and the distance to the nearest urban cancer care facility with similar programs. In total, 513 patient encounters took place, including those listed in the table as well as 37 store-and-forward tele-dermatology consults and 2 tele-family visits.

Discussion

The NPCCTN exceeded our goals in terms of the number of patients served, number of participating sites that attended, and geographic reach. Keys to success included resolution of technical issues, gaining provider and community acceptance, working closely with respected tribal members and local staff, understanding tribal governance and approval processes, and addressing cultural competency for academic personnel. The project's success demonstrates the importance of community involvement in designing and implementing telehealth systems. Others have reported that user participation in the

Table 1. Native People for Cancer Control Telehealth Network Summary of Activities

	NO. OF PARTICIPANTS OR CASES			NO. OF SITES			DISTANCE TO NEAREST URBAN CANCER CARE FACILITY
	SERIES' TOTALS	RANGE	MEAN	TOTAL	RANGE	MEAN	RANGE
Support groups and Cancer 101 presentations	242 (some duplicated, i.e., attended more than once)	6–57	36	25	1–11	6	39–1,190
Educational presentations	369 (some duplicated, i.e., attended more than once)	1–36	13	29	1–10	5	60–1,100
Case conferences	129 cases	0–27	10	22	1–8	3	0–1,190
Telepsychiatry consultations	103 case consultations	3–28	15	2	2	2	81–237

Note: Table does not include 37 store-and-forward tele-dermatology consults and 2 tele-family visits.

design and development of information systems increases the likelihood of successful implementation and utilization of these systems,^{24,25} users' satisfaction,²⁶ and users' perceptions of applications' utility.^{27,28} Lack of communication and collaboration, on the other hand, between end users and designers is often linked to failure of IT implementations.²⁹ End-user participation is critical in systems involving changes in healthcare delivery processes and patient-provider communication. We addressed end-user participation through technical assistance, hardware and software selection and installation, and meaningful communication with all stakeholders.

A key to the accomplishments of NPCCTN was culturally appropriate communication and cultural competence training. Awareness of how culture can affect communication is essential. For example, the words "positive" and "negative" can have opposite meanings when used in the context of cancer (e.g., a positive lymph node). Notably, the literature suggests that some tribal populations bring distinctive communication patterns to the medical encounter, including culturally specific metaphors,³⁰ disease models,^{31,32} avoidance norms,^{33,34} and word usages.³⁵ For instance, interviews with AI patients with chronic pain reveal that they underemphasize pain and disability, describing even severe symptoms with vague terms such as "ache" or "discomfort."^{36,37} And, although both provider and patient may be speaking English, world view, lifestyle, and life experience can create "different languages." Such culturally grounded differences in communication style may potentially contribute to a failure to recognize cancer symptoms or treat cancer pain, underscoring the need for and value of cultural competency training.

Providers and researchers must also be familiar with the communication style and conventions of AI/AN communities.³⁸ Although providers practicing at academic medical centers use e-mail as a primary communication device, e-mail communication was not always feasible or as effective as in-person visits and/or telephone calls in AI/AN communities. The value of the spoken word and art to teach and provide outreach activities in AI/AN culture cannot be overemphasized. Also, timelines can differ dramatically between urban and rural and between AI/AN and non-Native communities for a variety of reasons including governance structure, pace of life, and priorities. Including AI/AN faculty and staff in the teleoncology program, and cultural training for non-Native staff, helped address these issues. Additionally, strong working relationships with the Alaska-based NPCCTN staff and the Alaska Rural Telehealth Network staff have been essential to increasing outreach in Alaska and have resulted in increased participation in NPCCTN activities.

Our involvement within our partner communities, outreach activities, cultural competence efforts, and the collaborative nature of our partnerships increased the project's visibility in local communities and helped the NPCCTN to gain the trust of patients and providers. Finally, community-based and collaborative project implementation, continuous needs assessments, and evaluation were vital to maintaining partner engagement and providing true value through this project. This result was achieved through strategic planning meetings that brought together representatives and community stakeholders from our partner tribes and organizations and

members of the telehealth project, including individuals with expertise in technical, clinical, and educational areas, to address content, needs, and sustainability plans.

This study provides insight into the IT and cancer care infrastructure and needs of AI/AN communities. In general, little is known about the organizational readiness of AI/AN communities to adopt telehealth initiatives and the limitations of existing software, hardware, and human resources infrastructure to support IT healthcare applications in rural and underserved settings. Our findings suggest that the challenge is not so much the availability of hardware, but the need to customize software, work-flow procedures and processes to address the needs of the setting, to train end-users, and to provide useful and user-friendly telehealth interventions that address the needs and expectations of their target audience.

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