



Responding to American Indian Communities: Southwest American Indian Collaborative Network (SAICN) Cancer Educational Activities

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ABSTRACT

Developing educational materials and providing trainings in American Indian communities is a highly rewarding activity. However, to do so successfully a number of complex issues must be faced and cultural-tailored strategies to promote awareness must be developed based on the unique traditions of each tribe. In this paper we describe the educational activities conducted over a four year period by the Southwest American Indian Collaborative Network, a project funded by the National Cancer Institute's Center to Reduce Cancer Health Disparities. Activities fell into two broad areas: dissemination of cancer information through trainings and workshops and development of culturally-tailored educational materials.

Key Words: Health education, American Indians, cancer disparities

INTRODUCTION

In 2004, the Southwest American Indian Collaborative Network (SAICN) was awarded a five-year community network program grant from the National Cancer Institute, Center to Reduce Cancer Health Disparities (NCI-CRCHD) to eliminate cancer health disparities among American Indians in Arizona, Utah, and Nevada. SAICN, a multi-agency partnership between the Inter Tribal Council of Arizona, Inc. (ITCA), the Phoenix Indian Medical Center (PIMC) and the Mel and Enid Zuckerman College of Public Health (MEZCOH) and Arizona Cancer Center (ACC) at the University of Arizona works to close the gap between the health-needs of the American Indian communities within the

three states and the promise of cancer prevention and control through participatory education, training and research.

The fundamental goal of the SAICN is to significantly improve access to and utilization of beneficial cancer interventions in American Indian communities to reduce cancer health disparities. To achieve our goal, SAICN developed a core organizational infrastructure to support community-based participatory activities and effective partnerships between tribal communities, cancer prevention/care delivery systems, and research discovery/development systems at many levels to increase and sustain delivery of beneficial interventions. Five separate but interrelated core work groups were developed to achieve our goal: (1) Data and Evaluation, (2) Outreach and Services, (3) Policy, (4) Research, and (5) Training and Education.

The Training and Education Core was established to promote cancer-related education, training and outreach activities among tribal communities, tribal health departments, clinicians, case managers, and American Indian graduate students and university faculty. Our primary hypothesis is that if we are to improve access to and utilization of beneficial cancer interventions in American Indian communities, education and training must respond to community interests. Working with the SAICN Cores and the SAICN Community Advisory Board and Steering Committee, we identified gaps and opportunities for potential partnerships in cancer education and training activities. These include: cancer training and conferences, cancer outreach, information and dissemination, and the development of educational materials.

In this paper we describe the culturally-tailored educational activities developed and conducted by the Southwest American Indian Collaborative Network (SAICN). These activities consisted of training workshops for health providers and community members, participation in health fairs, and development of conference workshops on spirituality and cancer, and on resilience and historical trauma. The development and dissemination of unique educational materials including an interactive genomics glossary, innovative cancer education materials, and a spiritual care toolkit are essential measures in building on the cultural strengths of delivering cancer education and reducing cancer health disparities among American Indians in the Southwest.

Background and Significance

Cancer data on American Indian populations are limited, inconsistent and often do not reflect the increasing impact of the disease in tribal communities. While numbers are small, making it difficult to calculate incidence rates, it is well established that American Indians suffer disproportionate cancer mortality (Trends in Indian Health, 1997; Espey et al., 2007) and indicate increased cancer incidence (Trends in Indian Health, 1997; Espey et al., 2007; Wiggins et al., 2008). While these findings suggest the need for more cancer awareness and education, this can be a challenge in many American Indian communities. Efforts are hindered from the start as there are only a few established cancer programs in tribal reservation communities that conduct outreach, education, and offer early detection services. While there is a lack of cancer programs and resources for American Indians, the SAICN Training and Education Core worked diligently to provide cancer resources for American Indian communities in Arizona, Utah and Nevada.

Since cancer is primarily a disease that occurs later in life, it becomes more challenging to convince American Indian elders to participate in cancer screenings (ICC website <http://iccnetwork.org/cancerfacts/ICC-CFS2.pdf>. Accessed 01/29/10), especially since there may not be a term for cancer in many Native languages (Burhansstipanov & Hollow, 2001). If a term for cancer exists, it is commonly described as either a “disease that will not go away” or “sore that cannot be seen” which often

reinforces cancer myths and misconceptions. While many American Indians remain connected to their cultural ways, some cultural traditions and practices may present barriers to cancer education. For example, some tribes believe that it is inappropriate to carry ill-health messages. Some believe that cancer is an obscene, unspeakable, and shameful condition that is related to sin or guilt (Coulehan, 2003). For many of the traditional American Indian elders it may be deemed immodest and thus not culturally acceptable to speak of and/or illustrate screening methods for the breast, colon, and genital cancers. Despite the proven effectiveness or availability of cancer screenings, some American Indians may be less likely than others to seek medical care for conditions that are treatable and curable (ICC website <http://iccnetwork.org/cancerfacts/ICC-CFS2.pdf>. Accessed 01/29/10); and they may opt to see a traditional healer or medicine man for a traditional healing ceremony (Coulehan, 2003). Nonetheless, the Western medical treatment is becoming more acceptable (Coulehan, 2003) especially as more American Indians are beginning to reside in urban areas for employment and education opportunities (ICC website <http://iccnetwork.org/cancerfacts/ICC-CFS2.pdf>. Accessed 01/29/10).

METHODS

The Training and Education Core was established to promote cancer-related education, training and outreach activities among tribal communities, tribal health departments, clinicians, case managers, and American Indian graduate students and university faculty. The SAICN Training and Education Core was comprised of individuals who are experienced trainers and educators in American Indian communities and the leadership is composed of two co-chairs who convened quarterly meetings. Membership of the Training and Education Core included the Health Educator from ITCA, the Oncology Specialist from PIMC, a representative of the Chaplains Association at PIMC, ITCA Staff, Health Promotion faculty from the Zuckerman College of Public Health, the American Cancer Society and members of the Arizona Comprehensive Cancer Coalition. The members were identified by the Training and Education Core group, the SAICN Community Advisory Board, the SAICN Steering Committee or recommended by tribal representatives and/or programs. The Training and Education Core convened meetings quarterly to address concerns in developing and supporting community-based participatory educational activities; in addition to developing effective partnerships between communities, cancer prevention/care delivery systems in order to increase and sustain delivery of beneficial cancer educational interventions.

The Training and Education Core integrated tribal community feedback into the cancer-related education and training activities, in addition to working with the other SAICN Cores and SAICN Community Advisory Board and Steering Committee in order to identify gaps and opportunities for potential partnerships in our cancer education and training activities. The co-chairs presented information on cancer and gathered input from community leaders and members at SAICN Community Advisory Board meetings, at Steering Committee Meetings, Primary Partner meetings and at Core meetings. A list of potential cancer education projects were listed and then prioritized and voted by the Training and Education Core. The Cancer Education and Training work plan focused on 1) providing Cancer 101 training workshops for health providers and community members, 2) increasing cancer outreach through participation in health and wellness events 3) developing two conferences on (a) spirituality and cancer, and (b) resilience and historical trauma 4) creating skilled-based learning opportunities for students and tribal communities; and 5) developing and disseminating educational materials including an interactive genomics glossary and a spiritual care toolkit.

As the teachings and beliefs vary among American Indians, it is becoming more apparent to adapt the [cancer] health education messages and outreach efforts that engage a wider audience

that includes new and innovative methods that still integrate cultural elements. The activities and programs described in this paper demonstrate the increased role of community members in community-driven cancer education efforts for their respective communities. The projects allow for development in cultural awareness and sensitivity that have addressed the specific health needs of American Indian communities in addition to providing field experience for American Indian graduate students and employment for local community members.

RESULTS

Training and Educational Activities

Activities conducted by the Training and Education core included both the development of culturally tailored educational materials and the dissemination of cancer information. The design of culturally tailored products was essential to the education and training process. Training and education activities included “Cancer 101,” a cancer curriculum for community health providers, cancer prevention awareness and activities at community health fairs, conferences on spiritual care and on historical trauma, and opportunities for American Indian graduate students, health professionals and para-professionals, and tribal communities.

Cancer 101

The Cancer 101 curriculum was developed through a collaborative effort between the Northwest Portland Area Indian Health Board’s Northwest Tribal Cancer Control Project, the Mayo Clinic’s Spirit of the E.A.G.L.E.S. program, the National Cancer Institute Cancer Information Service (NCI CIS), and the Fred Hutchinson Cancer Research Center. The curriculum was designed as a cancer education and training program to help community-based health professionals gain a better understanding of basic cancer information. The Cancer 101 curriculum includes the following seven modules: 1) Cancer among American Indians; 2) What is Cancer? 3) Cancer Screening and Early Detection; 4) Cancer Diagnosis and Staging; 5) Cancer Risk Factors and Risk Reduction; 6) Basics of Cancer Treatment; and 7) Support for Patients and Caregivers.

The SAICN Training and Education core team tailored the existing Cancer 101 for American Indian tribes in the Southwest by including southwest regional cancer incidence and mortality data, by listing the top five cancers for American Indians in the southwest, by collaborating with regional health programs, and by modifying the length of the training into 30- to 90-minute sessions to fit the schedules of tribal members. The Cancer 101 training was made available at no cost to community health representatives (CHRs), health educators, cancer support group members, and others interested in advocating for and delivering the cancer information with family, community members or coworkers. From 2005-2009 SAICN has conducted 12 Cancer 101 training workshops in tribal communities with over 200 participants.

The information covered during the Cancer 101 trainings can be used in multiple ways. The curriculum materials can be condensed and presented as health topic presentations during health fairs and expositions, and/or as conference breakout sessions. During the Cancer 101 trainings, the SAICN often invited other programs and organizations to set up exhibits for participants to receive additional resources from cancer-related programs. In addition, local individuals and members of organizations were encouraged to serve as presenters for sections of the Cancer 101 curriculum. Individuals from the local Indian Health Services (IHS), tribal senior centers, women’s health, community health representatives, community tobacco education and prevention programs, and the Radiation Exposure Screening and Education Program (RESEP) contributed to these cancer trainings by serving as presenters, exhibitors, and/or training hosts.

In addition to increasing cancer education, the Cancer 101 provides a networking opportunity for

individuals to become acquainted with one another and with the services that each entity provides. This networking allows often isolated communities and health professionals to share resources and combine efforts once they learn who is interested in partnerships and what information is available. Further, the program demonstrated that, when local IHS doctors or nurses introduced and presented the cancer modules, participants may begin to feel more comfortable discussing their health concerns with them in a doctor's office.

The SAICN has also created new modules when the Cancer 101 trainings linked the tribes to the Radiation Exposure Screening and Education Program (RESEP). RESEP is a federally funded program that helps document claims under the Radiation Exposure Compensation Act (RECA). In addition, RESEP provides educational services to those who resided in the affected areas and were exposed to radioactive fallout due to U.S. atmospheric nuclear testing during 1942 and 1971 (i.e., "down winders" and on-site participants). The program provides public education and information on cancer screenings for uranium miners, millers, and ore transporters and down-winders. Uranium mining occurred on tribal lands located in the southwestern United States and many American Indians spent years working in the mines and mills (Brugge & Goble, 2002).

The Cancer 101 trainings received positive evaluations indicating an overall increase in knowledge across all modules and an appreciation for providing cancer-related resources to the community. Many participants indicated that they were anxious to learn more about specific cancers and eager to share their knowledge with others. One participant stated, *"I plan to educate my community by giving a lot of information with the handouts and places they can go for further information."* Another stated, *"I plan to read the material on Cancer 101 and educate through our Native tongue."* Other comments include: *"I understand cancer a lot better...I'd like to see you all come back and speak to the elders...I know they'd love to hear speakers like you here."* *"This training was very helpful to me and the staff...It was very helpful and encouraging having Native Americans doing the teaching and the doctor was very good!"*

Cancer 101 trainings have been shown to be essential for emphasizing the importance of practicing early detection methods, in combination with delivering preventive messages regarding health behaviors associated with reducing cancer risks.

Health and Wellness Events

SAICN Training & Education core members also delivered cancer education during health fairs, expositions and rodeos that targeted American Indians. The well-attended health fairs were sponsored by tribes or local hospitals, including the Phoenix Indian Medical Center. Participants were encouraged to interact with vendors and visit a specified number of information booths in order to qualify for prizes.

The information provided included verbal interaction, anatomical models, charts, and distribution of printed educational materials such as handouts and brochures. The educational materials included an assortment of published resources from numerous local and national health and cancer related organizations as well as American Indian specific print materials that were either free or available for purchase. The education materials were selected for their utility for the lay public and their ability to convey easy-to-understand messages.

The **Hoops for Awareness** events were a series of basketball clinics and health wellness fairs presented by Right Touch Basketball (RTB) Training and Development. The SAICN collaborated with RTB with the goal of promoting physical activity and cancer awareness among American Indian communities through basketball. Most American Indian sports enthusiasts agree that basketball is highly valued among Native communities. It allows for individual play and success, yet relies on a sense of camaraderie among players, just as traditional games were a way for warriors to physically prove themselves through competitions involving running, hunting and endurance (Pember, 2007).

The Fort Mojave Indian Tribe (FMIT) hosted the first Hoops for Awareness event on June 27, 2009. This project was guided by a SAICN intern who was confident that the event would spark the interest of the FMIT community. The basketball clinic and motivational speeches were presented by Kwame' Hymes (RTB Founder) and Sam Stith (RTB Director & Former New York Knicks). Both are cancer survivors who are committed to raising cancer awareness through basketball.

The basketball clinics were conducted by addressing game fundamentals and sportsmanship, while family and community members were encouraged to visit the health exhibit booths. The Fort Mojave Health Department was responsible for coordinating and advertising the health fair, while the Fort Mojave Recreational Department was responsible for recruiting 50 youth aged 8 through 12 and another group of 50 youth aged 13 through 16. The SAICN produced the materials for advertisement of the Hoops for Awareness event in addition to contributing towards food and drinks. Various health programs within the FMIT set up booths to distribute information and discuss specific health issues such as diabetes, dental, substance abuse, mental health, and cancer prevention.

The majority (80%) of the participants evaluated the Hoops for Awareness event as excellent while the remaining rated the event as good. Most (76%) participants rated the Boys & Girls Club as an excellent location for the Hoops for Awareness event, while 20% of the participants rated it as good and the remaining rated the location as fair. The health fair exhibits were rated as excellent (73%), good (24%), and fair (2%). The majority of participants (76%) rated the motivational speaking as excellent, while the remaining rated it as good. Over half of the participants (65%) rated the length of time spent on the motivational speaking as excellent and the remaining rated it as good. Both Sam Stith and Kwame' Hymes received excellent ratings.

One participant stated that they learned that "good decisions make for better living, no matter what hits us. Cancer is not the end of life - just different dreams - maybe even better."

Participants stated that the part they enjoyed the most was the motivational speaking and watching the kids play basketball. One participant stated that the message of the motivational speaking "was to never give up on our dreams." Another stated that "it was very comical watching the kids enjoy themselves." Others stated that they enjoyed the interaction with the community and that next time the parents/grandparents should participate too since it's good to show families learning and playing together - not just the kids. When participants were asked how they will benefit from the information provided, most stated that they will try to "take better care of my health for my family by getting regular health check ups, eat healthier, learn about available screenings, exercise, and encourage young people to accomplish their goals."

Since this event, Right Touch Basketball (RTB) has launched the "Athletes 4 Awareness" program in which they provide athletic training clinics with former basketball, baseball, and football professional athletes. The organization raises awareness in the areas of cancer, heart disease, diabetes and healthy lifestyles. The FMIT has also started the second round of planning and coordination of the basketball program known as "Night Side." The basketball project addresses many issues, including healthy lifestyles and good citizenship. Working in partnership with various FMIT departments (e.g., Health, Police, Fire), Night Side uses positive role-models to engage and inspire young people and promote positive behaviors.

Conferences and Workshops

Spiritual Care Conference: Addressing spiritual needs has long been an integral part of health care for American Indians and their families when seeking wellness and healing from illnesses. Long before the practice of Western or modern medicine, traditional Indian practitioners approached their patients as whole persons and the goal of restoring health included the restoration of spiritual well being. The reliance upon spirituality and interpersonal relationships between provider, patient, and

families was and is today, an important part of the provision of cancer care with American Indians. To address this important but often neglected part of health and healing, a two-day workshop entitled "Celebration and Ceremonies for Life's Transitions: Implications for Cancer Care with American Indians" was sponsored by the SAICN in March 2007.

Over 200 people attended the workshop held at the Heard Museum in Phoenix, Arizona. The conference was overwhelmingly well received as personal stories were shared and collective spiritual strength was experienced by those affected by cancer and working in cancer care. The majority of conference attendees were either American Indians, cancer care providers (e.g., spiritual care provider or health care provider), and/or individuals had been affected by cancer. That is they were living with cancer, were a cancer survivor, were a family member and/or caregiver of a cancer survivor/patient. Presentations such as "Cultural Perspectives on Modern and Traditional Medicine," "Healing Ceremonies," and "Keeping the Spirit Strong" provided different perspectives on how persons living with cancer and their families can not only survive a cancer journey but spiritually grow and heal through the experience. As one attendee stated, *"The stories really helped put a face, a personal side, to the problem of cancer."*

Conference on Resilience in the Face of Historical Trauma: In an effort to provide community members and university graduate students and faculty with knowledge of the models of building resiliency in the face of historical trauma, the SAICN was a sponsor of a full day conference entitled, *"Reversing the Trend: Resiliency in the Face of Historical Trauma."* This conference, which was held at the Mel and Enid Zuckerman College of Public Health, University of Arizona on April 18-19, 2008, drew over 70 participants from across the Arizona. The conference was planned, implemented and evaluated by graduate students in the College of Public Health and two SAICN Student Interns/Junior Investigators.

The conference had two primary goals: 1) to focus on cultural aspects that encourage resiliency in the face of historical trauma; and 2) to investigate actual methods to increase resiliency within communities that have and continue to experience historical traumas. Within these goals, participants were provided with awareness, ideas, and methods to implement cultural resiliency that could promote individual and community healing.

The conference planning committee selected presenters from different indigenous groups around the world, as historical trauma is not isolated to one group of people. Presenters were selected based on the body of their work, expertise and the professional and personal experiences using cultural resiliency methods to address historical trauma. Presenters were asked to make the workshops as interactive as possible and to provide some tools or resources for each participant to leave with and use in their community, workplace or personal life.

The conference began at an opening evening reception, with an emotionally moving opening address entitled, *"Feet on Country,"* by the Samia Goudie, a Bundjalung Mununjali woman from the East coast of Australia and a Fullbright Fellow, Lecturer in Indigenous Health at the University of Queensland, and a recipient of the Torres Strait Islander Award. Her presentation focused on the inter-generational trauma caused by the Australian government policy of stealing or forcefully taking Aboriginal children to missions, reserves and placing them in white homes, often to become servants. These children came to be known as the *Stolen Generations*.

Ms. Goudie shared her story of being a part of a *Stolen Generation* and believed that one must forgive to begin healing historic traumas. She accredited her resiliency to being able to forgive and to thrive so that she could tell her story. Interestingly, the audience response was divided as some did believe forgiveness was a key to resilience while others, who were not focused on resilience, did not believe they should forgive those who caused traumas that span generations, particularly because

oppression continues in communities today and is committed by the same dominant culture.

The conference continued with a second powerful keynote address entitled, *"500 Years of Indigenous Resistance: Is Social Inclusion Possible in Latin America Today?"* This talk was delivered by Dr. Eliane Karp-Toledo, the Former First Lady of the Republic of Peru and a Visiting Lecturer at Stanford University. Dr. Karp-Toledo began by describing the tragic story of the Indigenous struggles in South America against the Spanish conquistadors and the Catholic missionaries. Her presentation contained graphic historic pictorials that depicted scenes of warfare, slavery, and persecution. Her presentation was very effective in conveying the historical trauma experienced by Indigenous groups in South America. Dr. Karp-Toledo explained that the historic brutal and traumatizing experiences of colonization have perpetuated the continual marginalization of the social and political status of Indigenous People in Latin American countries. A panel discussion followed, in which presenters shared their personal experiences with historical trauma that were often compounded by stress, racism and oppression.

Following the panel, two interactive breakout workshops were offered: *"We Walk Together,"* led by Samia Goudie; and *"Healing the Generations: The Multigenerational Trauma Cycle and its Impact on American Indians/Alaskan Natives,"* led by Carrie L. Johnson (Dakota), PhD, Licensed Clinical Psychologist. A closing workshop featured the staff and youth from Native Youth Empowerment Project who presented *"Building Resilience Through Native Youth Empowerment."* These students showed the artwork they had developed and talked about the effect of the program on their own lives.

The overall conclusion of the participants of these workshops was that 92% (N=37) felt they increased their knowledge on how to use resiliency methods to heal historical traumas. One participant stated, *"I have really enjoyed the workshops. They have inspired me to find out more about my culture and traditions."* Another participant stated, *"The [workshops] remind me to remember Indigenous peoples from other places. Although we are from different places many of the same issues are universal."* Additionally, 96% (N= 37) of the participants indicated that they wanted to learn more about resiliency and historical trauma.

The overall conference evaluations suggest that there is a need for further study and development of resiliency models that can be used to foster healthy outcomes in recovering and healing from historical traumas. In addition, the evaluations imply that conferences like this one are important because they provide a venue for increasing individual and community awareness of models of resiliency that are currently being used to overcome historical trauma. These models include helping to build healthy families by drawing on cultural traditions that strengthen relationships. Further studies need to be conducted on models that focus on resiliency to understand and analyze underlying causes, contributing factors, healthy outcomes and effectiveness in hopes they lead to evidence-based interventions.

Learning Opportunities

Student Internships: A policy of the SAICN was to involve American Indian students from all three of Arizona's universities (University of Arizona, Arizona State University, and Northern Arizona University) in various aspects of the network's projects, and through that involvement provide them with support and the development of important skills. This involvement came in the form of paid internships resulting in the development of an interactive genomics glossary (described below, under educational materials) and the development and implementation of the Hoops for Awareness community cancer event described above.

Work on the genomics glossary began when four students, representing all three universities, were hired and began to study genomics terminology, working with the scientific definition to produce a lay definition appropriate for local communities. Once the terms were defined, the interns worked with the Walter Cronkite School of Journalism at Arizona State University to record both scientific and lay terms. Interns also shared their progress at SAICN primary partner and educational core meetings and prepared posters for presentation at the Cancer Health Disparities Summit in Washington DC. Of the four students who contributed to the development of the genomics glossary, one has gone on to pursue a Doctor of Public Health (DrPH) degree in genomics and public health at the University of Washington. Another student is now actively involved in preparing a workbook that will be distributed with the genomics glossary project (described below).

Digital Story Training: Throughout history, stories have been used to teach, express, advocate, and organize groups of people. It is through the sharing of stories that people remember their past, understand their present, and imagine their future. For public health professionals, stories can be an effective tool to create dialogue on a public health issue, to conduct health education outreach activities, and to increase awareness of health issues (Hodge, Pasqua, Marquez, & Geishirt-Cantrell, 2002).

The SAICN introduced media enhanced storytelling training— called “Digital Storytelling” — to tribal communities and health professionals. Digital storytelling is an innovative and visual health education tool for communities to use to increase knowledge about a health topic and to create dialogue on a topic. The process integrates the participants’ own voice and existing images such as photographs and scanned images into brief first-person narratives that can be used to engage others or educate them about a given subject.

The digital storytelling training involves two stages in a two- to four-day workshop. The first stage is an intensive production workshop, where workshop participants go through the process of creating their own digital stories. Participants learn how to craft a script, develop a storyboard, record audio, scan and download images, and edit using digital video software that is available for free on the Internet. Participants are requested to keep their narrative to one page and develop a digital story that will last from two to five minutes. In the second stage, participants receive follow-up support in program implementation and technical assistance as the participants begins to integrate digital storytelling into their work.

After the digital stories are created, participants evaluate the digital stories through a process of informal reflection. To begin, the participants are asked to share their digital story and give informal reflection comments about their making-a-digital-story experience. After their digital story is shared with everyone, comments are invited from other participants. Key questions that are asked included (1) what parts of the story touched you, (2) what images most impressed you, (2) what reaction to the story would you like to share with the storyteller?

Thus far, SAICN staff members have conducted six digital storytelling trainings for six communities and organizations. The stories developed covered organizational programs and activities and highlighted such things as 1) health educators’ activities at the Great Native American Smoke Out, 2) Hopi Cancer Patient Assistance Fund, 3) the Hopi Breast and Cervical Cancer Program, 4) the Inter Tribal of Arizona Inc., 5) Hualapi Health Department and 6) Fort Mojave Health Department. The stories were developed by participants in order to provide information on specific programs, encourage participation into programs, and stimulate discussion about a health topic.

Evaluations of the Digital Storytelling trainings indicate 100% (n=20) satisfaction with the workshop and with the acquisition of technical skills. Comments from participants include the following: *“I didn’t think I could do this, I thought it was going to be hard...but it turned out to be easier*

than I thought.” “I can use this (digital story) in the waiting room...so they can see a video on health instead of just waiting there?” “I can use this so we can get more money for our program.”

Training in Technical and Science Writing: A two day class in science and technical writing was developed and taught by university faculty SAICN partners. This class was attended by over 26 students from eight agencies and tribal communities. It focused not only on issues related to formatting, but issues of handling writers block, rules of grammar, and identifying appropriate journals and finding valid sources of information. The classroom experience, included both a lecture and hands-on format, and each student was provided with a laptop computer connected to the internet. The instructors worked with each student individually and discussed topics and themes and, if requested, a critique was given. Students, who all evaluated the class as very successful, were then also given follow-up assignments that were to be returned for review and comments.

Tribal Small Grants: A final educational project funded by SAICN included training and technical assistance was the Small Tribal Community Grants Program. Seven tribes/communities were awarded small grant funds based on the communities’ research interest and program development as related to cancer disparities among American Indian communities. The research projects promoted a Community Based Participatory Research approach such that the communities identified and selected the best practices for cancer education services, gaps in services, and effectiveness of existing services and programs. The seven tribes/entities funded included the Gila River Indian Community, Hopi Tribe, Hualapai Tribe, Indian Health Board of Nevada, Kaibab-Paiute Tribe, San Carlos Apache Tribe, and the Tohono O’odham Nation.

The Gila River Indian Community focused on establishing a cancer roster that would identify the boundaries and function of the cancer care system in addition to conceptualize a system for tracking tribal members diagnosed with cancer who did not seek care at the tribal health care corporation or its Contract Health Care Facilities. The project anticipates the establishment of a database for Navigators to track patients both on and off the reservation.

The Hopi Tribe focused on developing a patient navigation system for community members diagnosed with cancer. The data obtained from this study will be used to prioritize the needs to help cancer patients and their families travel the path from cancer diagnosis, treatment, survivorship and/or death.

The Hualapai Tribe focused on developing a “Community-based Model for Cancer Education” in which eight (8) interactive cancer educational modules were offered once a month in community gatherings. The intervention module was adapted to the interests and level of cancer knowledge. The goal was to revitalize the Hualapai traditional beliefs and incorporate the healing songs into cancer awareness and prevention trainings and events.

The Indian Health Board of Nevada focused on developing and implementing culturally-appropriate marketing strategies to raise cancer awareness among American Indians living in Nevada. The Kaibab-Paiute Tribe examined the community’s health beliefs, knowledge and behaviors regarding cancer and their behaviors regarding cancer screening and early detection methods. In order to prevent the incidence and spread of the Human Papillomavirus (HPV) in the San Carlos Apache Tribal community, the study examined the community’s health beliefs and the cultural constructs regarding HPV.

Finally, Tohono O’odham Nation focused on developing and identifying a mapping process of the cancer diagnostic and treatment network project between the Indian Health Service, contract health care and private providers for the community members diagnosed with cancer.

The research projects identified and selected among each entity ranged in methodologies, including focus groups, surveys, and/or assessments of knowledge, attitudes, beliefs, and behaviors related to cancer, cancer risk, and cancer protective factors. Prior to funding, the Inter Tribal Council of Arizona, Inc. established Memorandums of Understandings with the tribal councils and tribal health departments. The projects described above have progressed culturally acceptable programs. The development of a proposal to further develop, implement and evaluate appropriate and culturally sensitive interventions is a planned next step.

Educational and Training Materials

The second category of activities conducted by the SAICN Training and Education Core involved the development of innovative educational materials. These included the development of educational videos using local tribal people, the development of the 'Gathering Basket', a CD-Rom compilation of innovative cancer educational materials, and the creation of the interactive Genomics Glossary introduced above.

Education Video Projects: Addressing cancer health disparities that involve American Indians requires providing educational cancer materials that are culturally tailored, culturally sensitive, and appropriate for American Indians going through cancer treatment and for those who provide their care. Currently, few resources are available that specifically address spiritual and cultural aspects for American Indians. The SAICN, in collaboration with Lizard Light Productions, the photographers for the Spiritual Care Conference, saw the potential for reaching a wider, diverse audience by developing videos on lessons learned and stories shared. Two videos on spirituality and cancer, that featured speakers and participants from the Spiritual Care Conference, were developed and have been widely shown and disseminated. These videos are part of a larger toolkit on spiritual care that is being prepared by the SAICN.

The first video, "Cancer Has Crept among Us," focuses on a family living in a rural reservation in northwestern Arizona and features the story of an American Indian cancer survivor and the many ways that cancer touched her life and the lives of many of her family members. This cancer survivor encouraged viewers to draw upon their spiritual and cultural traditions as a source of hope for the individual, his/her family and for the community. Her story was when she was a participant at the spiritual care conference with her daughter, she asked the question: "*Why is cancer killing my family?*"

The second video, "American Indian Attitudes and Values: An Integral Part of Cancer Care," features interviews with American Indian cancer survivors, family members, community leaders and health care providers. The goal of this video is to emphasize the importance of providing spiritually appropriate cancer care services for American Indians.

Both videos, along with a discussion guide booklet, are included as part of an educational toolkit on spirituality and cancer care for health professionals. The aim of this toolkit is to increase awareness and education about the role of cultural and spiritual aspects of cancer care among American Indians.

The Gathering Basket: *The Gathering Basket: Journey to Cancer Awareness*, is a CD-ROM and web-based (www.gatheringbasket.org) educational tool for Health Educators and Community Health Representatives (CHRs). It provides information and educational materials and resources on breast, cervical, colon, lung, and skin, testicular and prostate cancers which are the leading cancers for American Indians in this region. The Gathering Basket filled an important gap for tribal health educators. While community-focused education on cancer is generally delivered at health fairs, information and resources for tribal health educators and CHRs has been limited and focused

primarily on breast and cervical cancer.

The symbol of a basket was chosen for this project as American Indians have used baskets to fit the varied tasks of farming to gather, store and share food, medicines and give away as gifts. It is a local art, based on materials and dyes originating from the area. Like traditional baskets, this CD-ROM, the Gathering Basket, is a tool to gather information about cancer. A CD-ROM format was chosen due to limited or no internet access in rural American Indian communities. Most community educators only access the internet at work or at Indian Health Service facilities which limit access to downloadable materials.

The Gathering Basket provides downloadable Fact Sheets on each of the seven cancers. The fact sheets include information on signs and symptoms, tips on prevention and early detection and treatment. On the CD-ROM, each cancer module has a different colored ribbon corresponding to an affiliated cancer color. For example, the breast cancer page has a pink ribbon in the gathering basket, while the prostate cancer has a blue ribbon. The goal of each module is to educate men and women about the specific cancer: breast, cervix, colon, lung, skin, prostate and testicular. The objectives are to describe the cancer, when the cancer starts, where it starts, and why it starts. The CD-Rom is currently being field tested in the American Indian community.

Genomics Glossary: Through a collaborative process with the Translation Genomics Research Institute (TGen), Indian Health Service, and the three Arizona universities, the SAICN Training and Education Core developed a multimedia glossary of genomic terms, entitled "Talking Glossary of Genomics Terminology." This talking glossary is modeled after the "Talking Glossary of Genetics" project that was developed by the National Human Genome Research Institute. The glossary initially is available as a user-friendly CD and will eventually be an internet resource on the Inter Tribal Council of Arizona, Inc. website.

The glossary is focused on definitions of genomics terms related to cancer and how the field of genomics research can affect early diagnosis and treatment of cancer. This educational tool was designed to inspire more American Indians to learn more about translational genomics research and about the genetic tie to diseases that affect American Indians. The introduction of the CD includes audio and video commentaries of American Indian tribal leaders and/or elders. These commentaries provide a unique addition to the genomics project with tribal leader viewpoints about often controversial issues such as research, genetics, and the impact of cancer in tribal communities.

The glossary includes approximately 170 genomic and cancer terms along with illustrated diagrams. In addition to the written scientific definition, graduate students from Arizona's three universities recorded lay audio versions of the terms for non-scientific audiences thus allowing opportunity to increase health literacy by explaining genomic terms in lay language. To help conceptualize the terms in application, a written genomics workbook will soon be included to compliment the Glossary. This work book, titled "The Genomics Education Module," is being developed by a graduate student who participated in the recording of many of the genomic terms. The goal of the Genomics Education Module is to generate a broader understanding of genomics by helping provide an innovative and interactive way to better inform American Indians about genomics research and genetic cancers thus educate and empower American Indian students and community members. The module was based on the premise that the emerging areas of genomics and personalized medicine will have significant impact on the future of medicine and public health. Benefits for American Indian populations may be more widespread if the population has a greater understanding of the basic concepts and terminology.

The SAICN Web link: The Southwest American Indian Collaborative Network web link (www.itcaonline.com/saicn) accessible through the Inter Tribal Council of Arizona, Inc. main website, consists of several pages that provide detailed information about the cancer network, the purpose, the organizational infrastructure, partnerships and collaborations, and the project activities and events. The homepage provides an introduction of the SAICN grant program, the project staff, primary partners, funding sources, as well as the cancer network work plan objectives. A map of Arizona, Utah and Nevada is provided to illustrate the geographical distances between the tribes that are served by the SAICN project. Information on the Spiritual Care Conference and the two videos can be viewed on the SAICN web link. Information on the Talking Glossary and Genomics Terminology project as well as the Cancer 101 Trainings is also provided on the SAICN web link. Contact information for both projects is provided via the web link. Links to a number of national and local cancer organizations also are provided on the SAICN web link. Many of these organizations provide trainings, workshops, and grant opportunities. Partner organizations and collaborators also are able to post upcoming events or training workshops related to cancer.

CONCLUSION AND DISCUSSION

The primary goal of the Training and Education Core was to improve access to culturally-responsive cancer interventions for American Indian communities in Arizona, Utah and Nevada. Through the duration of the SAICN cancer grant, the Training and Education Core established and nurtured its trust through collaborations with the tribes and other entities that facilitate [cancer] health services for American Indians. An important basis of success for the SAICN training and education core was the involvement of tribal leaders, community members as well as the commitment of the primary partners: Inter Tribal Council of Arizona, Inc., Phoenix Indian Medical Center, and the University of Arizona. The inclusion of these elements was crucial in creating a comprehensive voice to reduce cancer disparities among American Indians.

While there continues to be a need for cancer resources for American Indians, the SAICN Training and Education Core facilitated training workshops and conferences for health providers and community members, participated in health fairs and cancer awareness events, hosted conferences that address spirituality and cancer, as well as resiliency and historical trauma. Workshops such as the Cancer 101 train-the-trainer series and Digital Storytelling were instrumental in facilitating opportunities for skilled-based learning related to, but not limited to, increasing participants' sense of ownership, confidence, and networking as related to cancer education. The development and dissemination of the *Gathering Basket: Journey to Cancer Awareness* and the spiritual care toolkit (including videos and discussion guide booklet) are fundamental in delivering cancer education and/or support, especially for those [communities] that may have either limited or no internet access.

The activities and programs described in this paper substantiate the value of American Indian community members responsive to the initiation and completion of tribally-driven cancer education and research projects. The SAICN Training and Education projects such as the Tribal Genomics Glossary and the Small Tribal Community Grants are inspirations of the cultural strengths of the tribal communities and they engage American Indian students and local community members. The cancer education activities included in this paper contributed to fulfilling the need for cultural-relevant cancer resources for American Indian communities in the Southwest.

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