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American Indian Attitudes & Values:
A video that highlights the importance
of spiritual care and cancer care
services

Presenter Disclosures

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The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

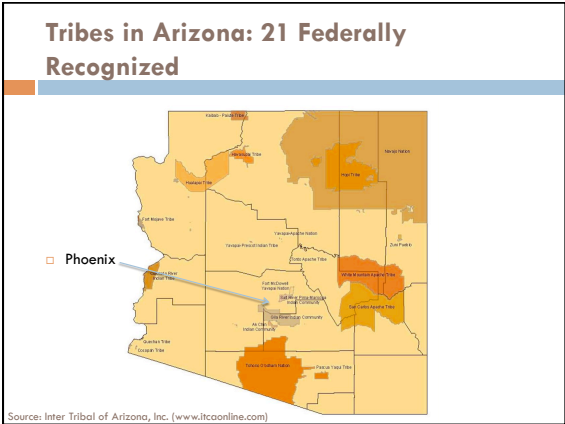
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The Southwest American Indian Collaborative Network (SAICN)

- Funding made possible for this project through the National Cancer Institute, Center for Cancer Health Disparities, Community Network Grant(U01 CA11469) whose aim is to reduce cancer health disparities among American Indians in the Southwest
- Partnerships:
 - Inter Tribal Council of Arizona, Inc.
 - University of Arizona Cancer Center
 - Phoenix Indian Medical Center

Long history of working together between partners and community collaborators



Spiritual Well-being and Health Care for American Indians

- Spirituality is an integral and expected aspect of care for American Indians and their families
- Traditional Indian practitioners approach patients as whole persons and spiritual well-being is a part of that care
- Interpersonal relationships between the medical provider, patient and families are recognized

Cultural Considerations in Cancer Care with American Indians

Addressing cancer in some American Indian (AI) communities is complex - culturally

- There is no word for cancer in most languages
- Perceptions of fear and possibility for no cure persist
- In some AI tribes, communicating about disease/illness can carry a connotation of bringing harm
- There are limited cancer educational materials specific to AIs

Spiritual Care Conference (March 2007)

- Over 200 attendees at "Celebration and Ceremonies for Life's Transitions" conference in Phoenix, AZ
- Speakers and participants shared their stories of how cancer had impacted their lives and those of their family and tribal communities
- Two videos were produced to reach a wider audience with the lessons learned and stories shared
 - Produced by SAICN and Lizard Light Productions, a locally owned American Indian business

Video Project Goals

1. Provide a greater understanding of and respect for AI spiritual and cultural needs when seeking cancer care.
2. Provide a greater understanding of AI ceremonies surrounding life transitions and how these can be integrated into the cancer care
3. Educate viewers about the vital link between spiritual care and medical care for AIs
4. Provide resources about cancer and cancer care for AIs

Meeting the need to develop Culturally and Spiritually Appropriate Educational Materials

- Purpose of the video project
 - Promote cancer awareness and education through the development of culturally and spiritually appropriate educational media
- Audience
 - AI cancer patients, family members, healthcare providers and community leaders.

“Why is cancer killing my family?”

- The first video “Cancer Has Crept Among Us”
- Features Linda Havatone, a Hualapai Indian. She shares her story of cancer survival as well as her family’s multiple experiences with cancer in a rural Indian community in northwestern Arizona.
- Linda and her family’s experience with cancer was first made known to us when Linda, while attending the spiritual care conference with her daughter, stood up during the Q&A time and asked, “Why is cancer killing my family?”

Keeping the Spirit Strong


- 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 on the importance of providing culturally and spiritually appropriate cancer care.

Video Production ...a story within the stories

- Highly collaborative: A year-and-a-half long process
- Media releases and permission for filming at various sites required local, federal, IRB and tribal approval
- Conference proceedings and transcripts guided the script as themes emerged from each person’s story and/or presentation
- Alex Maldonado, a local American Indian artist/flutist, had a family member who was affected by cancer, generously donated his music for both videos

Videos show positive impact

- Shown to diverse audiences:
 - Tribal workshops and council meetings
 - Caregiver conferences
 - Medical staff and cancer patients
 - Gatherings for faith communities
 - Educational forums for hospice workers and spiritual care providers
 - Cancer awareness and prevention events



"WE CAN SAY there is hope. They are not alone. Be brave, be strong. Now we can do what we hope to do to help ourselves."

— Linda Havatone, National Cancer Institute

Diagnosis: Head and Neck Cancer

An updated version of the video produced by the American Cancer Society, titled "Cancer: The New Normal," featuring Linda Havatone, was released in 2008. She released a second video, "Cancer: The New Normal," in 2009.

<http://www.youtube.com/watch?v=Philly-902-1>

The Voice of Experience

In 2000, Linda Havatone's daughter, Janette, discovered she had cancer. Linda Havatone, her mother, was diagnosed with breast cancer in 2000 and again in 2007. A public health expert in Epidemiology, Linda shared her story to inspire others to take action to prevent cancer.

Despite the repeated diagnosis in her life, Linda is choosing to look ahead. In fact, she, along with her daughter and several cancer survivors, founded and co-edited the book "Cancer: The New Normal" in 2008. The book provides cancer education and inspiration for cancer survivors and their families.

For instance, Linda said Janette referenced their stories to the producers of a cancer education video. It has been shared with numerous cancer prevention leaders in Washington, D.C., and continues to be used in her recent book, "Cancer: The New Normal." Linda also travels to other countries to speak and participate in national cancer awareness events, including National Cancer Day.


"We are grateful to have shared our story and to have inspired others. We know that Native American people don't want to talk about cancer, but we don't want to be the only ones."

"So, this was an honor speaking for the People. I am speaking for all Native People in the U.S."

"Because of my family history, yes, I'm still afraid. I don't know what is going to happen next. But I will do it. We need to take care of ourselves. Let me check up. You still have a life ahead of you!"

Videos show positive impact

- Linda Havatone continues to speak at national conferences to educate about cancer
- Hualapai tribe now has a Cancer Prevention Program



Janette is a cervical cancer survivor. Now she wants other women to know...

...that in the early stages, cervical cancer can be cured 100 percent of the time.

There is no shame. It's time to get your check up!

— Janette Havatone, Hospital

Videos show positive impact

- Jeanette Havatone, daughter of Linda Havatone, is a cervical cancer survivor
- Jeanette encourages women to get annual Pap tests

For cervical cancer, the message that Janette wants to share is straight to the point:

- Get your Pap test. (See pages 11 and 12 for the Tribal Breast Health program directory.)
- Don't wait for pain or any other physical symptoms.
- If your Pap test is an abnormal result, follow up by getting further testing.
- Be sure to show up for your follow-up appointment. Many times abnormal results are not cancer, and the second test will show you are cancer free.
- If the test does show positive for cancer, talk with your doctor about getting it treated right away.

Your chances for surviving cervical cancer are greater the earlier it is detected. A Pap test is the only way to diagnose pre-cancer and early stages of cervical cancer, which can be treated with a 100 percent cure.

See Janette Havatone's story on page 11.

Resources

- Discussion guide booklets for group facilitators is being developed for both videos

- Watch the videos on the Inter Tribal Council of Arizona, Inc. web site
<http://www.itcaonline.com/saicn/Resources.html>

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