



Native American Elders Diagnosed with Cancer: Access to Quality Care



Mary Nance
Kickapoo /
Hispanic
Dx 2000 breast
cancer

What is this issue?

- Many Natives do not trust western medicine and this delays us from getting into treatment.
- Indian Health Service, Tribal or Urban (I/T/U) Indian Programs are where we are likely to try to get help getting care, unless we have *private* health insurance.
- But, I/T/U Programs are so greatly under-funded by Congress that they rarely are able to provide cancer referral services / care to Native cancer patients.
- If we have to rely on I/T/U programs, the time period from when we had our biopsy diagnosing our cancer and when we finally get into care may be 6 months or longer. Our cancers continue to grow while we wait to get into care.

What are the problems or issues related to access to quality health care?

- Only about 1 out of 3 Natives have private health insurance that includes services like cancer care.
- Most I/T/U Programs rely on “Contracted Health Services” to be referred to another location for our cancer care.
- “Contracted Health Services” are under-funded by 40-60% of what is needed by the local Native organization.
 - Each year the I/T/U makes a list of the health problems of most importance for their community. This is a priority list.
 - If *cancer* is not among the top 5-10 conditions on the priority list, you may have to wait months until higher priority health problems are taken care of before you get your referral.
 - Most I/T/U programs run out of “Contracted Health Service” monies by late spring. The new monies come in on October 1st (fiscal year), unless there is a federal freeze.

What can you do?

- 🗑️ Contact Native American Cancer Research Native Advocates (see numbers and website below) and other resources listed on the Elders Resource Fact Sheet
 - 🕒 Do not give up hope.
 - ✍️ There are many resources available for people who need help paying for medications, getting transportation, being eligible for federal programs like Medicaid, Medicare, Americans with Disabilities
- 🗑️ Contact the I/T/U health committee to get their help for your “priority” to be listed higher than it is presently on the “Contracted Health Service” list
- 🗑️ See if your type of cancer is being included in a clinical trial that may also help pay for medications, transportations, and other forms of care.



Denver Native American Cancer Advocates
(303) 837-7163

National Native American Cancer Advocates
1-800-537-8295

“Native American Cancer Education for Survivors”
<http://NatAmCancer.org>

Native American Cancer Research
3022 South Nova Road, Pine, CO 80470-7830
303-838-9359; fax: 303-838-7629

The issues identified in this Fact Sheet are from intertribal focus groups held in 2006.

Thank you to those who participated



Co-Investigators :L Burhansstipanov; and LU Krebs; Developed through support from Colorado Program in Aging and Cancer; Project #9:2-5-26213 [PI: Byers NCI P20 CA103680]; Mayo Clinic's Spirit of Eagles Community Network Programs [NCI U01 CA 114609]; IHS [DHHS -6-0052 No. HHS1236200; 6076042400; 064-CPC];

What did elder Native patients say about this issue?

- 👤 *I got over being mad at the Indian Health Service, that took me about six months to do that. (04-21-06)*
- 👤 *[I have] a mistrust of Western medicine, so [I was] scared to go to the doctor. (04-13-06)*
- 👤 *[My mother] really suffered a lot and was in a lot of pain. They didn't have the best medicine for Indian people then. (04-13-06)*
- 👤 *"The radiation treatments. They made me tired, couldn't get home sometimes. Took me a long time to get home. I was taking a bus and the bright lights used to bother me and the sunlight. I couldn't see so I would wait until it cleared up. (04-04-06)*
- 👤 *"When I had to have my cancer I did not have health insurance so I had to go to my home reservation in [USA state] and have my treatment done there because that is where my health contract is. So I had to leave my family and go there...we don't want to be alone but it wasn't very much fun." (4-21-06)*
- 👤 *"Or people decide to go home to get their treatment and since we're living in the urban area, most of us have to live back there at least six months to re-establish residency. So by then your cancer has had a chance to grow a lot more. Which is a big issue." (4-13-06)*
- 👤 *[Native] people who have left the reservation and gone on to do other things in their life, when they get cancer, they come home. When they come back home they are really sick. Most of the time we are looking at an intense life care...care is not free. (4-21-06)*
- 👤 *Some pill that she took, I think it was about a \$100 a pill that kept her from getting sick. (04-04-06)*
- 👤 *[Native woman who had private insurance]. Even though she was sick, she wasn't like a lot of the other people in the cancer center with everybody throwing up. She didn't get sick like that, she got tired, but she drank the [anti-nausea medication] every day." (4-13-06)*
- 👤 *[My] sister was so gracious to come along side and give me that support; it was a 240 mile drive from my sister's house down to [the clinic].(04-21-06)*

Getting access to quality care
can be very frustrating!



What are common myths?

- 📦 MYTH: Cancer is a death sentence, especially for elders.
 - 🕒 Cancer may be in early stage, even though the patient is elderly when it is diagnosed. Many cancers tend to grow slower if they begin in someone who is elderly.
- 📦 MYTH: Elders have lived their lives and should not use the limited monies from “Contract Health Services” to try to extend their life.
 - 🕒 Patricia Cochran, Inupiaq,
“Every time an elder dies, a library burns”
 - 📖 This quote shows how important it is for us to help elders stay healthy and alive. We need our elders to continue to teach others.
- 📦 MYTH: Western Medicine is the only way to treat cancer.
 - 🕒 Many elders choose to not have treatment. They say the treatments will make them feel sick, and they do not feel very sick, even though they have cancer. They may choose to use traditional Indian Medicine, spiritual treatments and other alternative care. It is their choice.
 - 📖 *“We’ve seen some of our native people go home who have refused treatment, especially the elders, who say they’ve lived a long life and this is what the Creator planned.” (04-13-06)*
 - 📖 *“It is real important to know about alternative medicine”. (04-13-06)*
 - 📖 *I want to be free to take what I want. The choice shouldn’t be taken away from [me].” (4-13-06)*

What are Unique Issues affecting Elder Native American Cancer Patients?

- 📦 Delays in getting care may be due to mistrusting Western medicine (based on valid reasons) and believing that Indian are not given the *real* medicines for cancer.
- 📦 Elders sometimes refuse care so that there is more money left in “Contract Health Services” for children and youth (the next generation) to get their care.
- 📦 Most of our Native cultures make it difficult for younger family members to get our elders to talk about personal health problems they are experiencing. It is disrespectful to repeatedly ask the elder to talk about something the elder says s/he doesn’t want to talk about.