

EXECUTIVE SUMMARY

The Shared Cultural Knowledge and Beliefs about Cancer in an American Indian Community

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Native American communities face an ongoing challenge of effectively addressing cancer health disparities. Effective approaches to the prevention and treatment of cancer in communities requires more than simply measuring the “lack of knowledge” regarding cancer. It is critical to identify and describe the influence of cultural perspectives within the community. Cultural knowledge and beliefs have a direct influence on the ways communities chose to access health education, screening and treatment services.

The aim of this research study was to utilize a cultural consensus method to identify the cultural knowledge and beliefs about cancer in a southwest American Indian community. A community-based participatory research (CBPR) approach was applied at all stages of the study.

The methods utilized to answer the research questions include the results from both qualitative (i.e. interviews) and quantitative (i.e. rankings, pile sorts, survey) data (see attachment). The specific aims of the research were to answer the following questions:

- What are the community members’ knowledge and beliefs about cancer?
- Do they believe it can be prevented?
- Is there cultural consensus (agreement) in the community regarding the cause(s) of cancer?

- Do they believe it can be effectively treated or cured?
- What do they believe are reasons a person continues to live even after they are told they have cancer?

Research Methods Used

The phases of research that were completed to answer the research questions and the purpose of each were:

- 1) ethnographic interviews (n=20) – identifying themes or the content of items in the participants' cultural model
- 2) ranking of themes (n=16) – understanding the importance of the content of the cultural model
- 3) pile sorts (n=16) – the organization of the model
- 4) community survey (n=74) – whether the model is shared in the greater community.

RESULTS

What are the community members' knowledge and beliefs about cancer?

There was a fear of death or dying from cancer expressed by interview participants, based on lived experiences either directly or as supporting and involved family members/friends observing loved ones diagnosed with late stage cancer and often dying in less than a year's time.

“. . .as soon as you learn that someone has cancer, that it's pretty much something that they will always have. . .that is going to be life-changing, . . .could very well mean that they are going to die from this disease.”

“I went to the Indian public hospital . . . and they called me that they needed me to go back in and I did. I didn't know what it was. The doctor didn't really explain (it) to me and I don't know what she did but, after she got through, she shook my hand and she said. . . what did she say?. . .'I wish you luck.' And that scared me

. . . I cried all the way home because I thought, you know, I'm not ready to die. I don't have my clothes ready to die. My children are still, you know, still young and who's going to take care of them? All that thoughts went through my mind. . Who's going to take care of them, you know? I'm not ready to die."

Do they believe it can be prevented?

Among those interviewed, the results indicated that there was no agreement (consensus) on the importance of specific concepts of prevention.

However, there was agreement (consensus) on the organization of a cultural model that included:

- environmental factors - ex: avoiding – sun, chemicals
- healthy lifestyle - ex: exercise, diet

Among those interviewed (n=20), over half did not think it could be prevented and that is “just happens”:

“. . . if you don't know where it comes from, how can you prevent it?”

“I've never heard that you can prevent cancer. I've always heard it's just something that happens but I've never heard of the prevention so, if I hear about something or a presentation about preventing cancer, I definitely would attend it and educate myself more about that.”

Is there cultural consensus in the community regarding the cause(s) of cancer?

The results indicated that there was strong agreement (consensus) on a defined cultural model for the causes of cancer.

The model was organized into three categories:

- Environmental – ex: chemicals, mine/smelter
- Lifestyle choices – ex: tobacco, lack of exercise
- Traditional lifestyle – ex: changes from traditional diet and exercise

The results of a simple analysis of variance (ANOVA) test indicated that the interview participants considered environmental factors as the most important cause of cancer.

Those items in the cultural model that were ranked the highest in importance were:

- chemicals
- “downwinders”- exposure to 1950’s nuclear testing fallout
- mine/smelter – mine tailings/waste from a local copper mine
- exposure to the sun
- tobacco use
- cement plant – residual dust and particles

“. . . all of us have been here. . . it seems like no one’s doing anything about it. . . we had that young gentleman that passed away and then this girl. . .we know that so-and-so has cancer. And you begin to kind of associate them with living in this area and that there must be something that happened with this air pollution that caused that. . .How many people should know that they need to get a examination to find out whether they have cancer or not? And it just kind of runs through my mind that I really ought to be going to the doctor and I haven’t done it yet. . .“

Do they believe it can be effectively treated or cured?

Similar to the results about the prevention of cancer, there was no agreement (consensus) found regarding the importance of any specific types of treatment of cancer.

Although they identified different treatments (i.e. chemotherapy, surgery, radiation), when asked to describe what the treatments were or how they worked, many responded that they either didn’t understand how they differed from the

other, or they didn't know.

Some thought chemotherapy was similar to how dialysis worked, and still others described it as "a poison" that was injected to fight cancer.

There was agreement (consensus) on the organization of a cultural model regarding treatment, it included:

- spiritual/traditional ways – prayer, beliefs
- medical treatments – chemotherapy, radiation
- last stage/days – ex: hospice

When asked if they thought cancer would go away permanently after a cancer diagnosis and treatment, about half believed that it was possible that it could be cured. The remaining believed that there was no cure for cancer, and that there would always be a chance that it would return or come back.

"I don't think there's a cure for cancer. That no matter how you take the medications, or no matter what you do to your body . . . it seems like it's something that you have that would never, ever go away. . . like even now, I see a lot on TV. . . that they're still trying to find a cure for the cancer. . . they're still researching to try to find something. But I don't think . . . it will go away."

What do they believe are reasons a person continues to live even after they are told they have cancer?

During the interviews, when asked how a person is able to continue to live with a diagnosis of cancer, they discussed five different areas they felt had a direct impact on the quality of life of a cancer survivor:

- a change in lifestyle
- ongoing treatment and medical care
- support from family and friends

- their attitude
- the strength of their faith or spirituality

“ . . .she’s a very strong Christian person. She always says that going to Indian school that this is something that she learned and she said that . . . she doesn’t know where she would be today if it weren’t for that. And so she said, ‘I’ve lived this long with God’s help, that He loves me. That’s why He takes care of me.’ And I guess maybe it’s pain that she can bear, and so I really can’t say about anything else, other people, how they feel, what they think. I think most of the people that I know, that’s the thing that they say too.”

Several people mentioned the need for additional support that might be provided from a cancer support group, but there currently aren’t support group services offered in the community for survivors or their families. However, the closest cancer support group services are provided at the local medical center, a 30 minute drive from the community.

CONCLUSIONS

- Based on the findings, it could be concluded that there may not be agreement in the community on specific ways to prevent cancer because there may not be access to receiving a comprehensive cancer prevention education message.
- This could also be concluded regarding resource information about available and effective cancer treatment options
- The identified cultural model of the causes of cancer – environmental factors (including exposure to nuclear radiation/“downwinders”, toxic waste from mine/smelter, and particle dust from the cement plant) – is based on their lived experience, including knowledge of compensation

from the federal government to cancer victims and their families and knowledge of cancer cases and deaths in the community.

RECOMMENDATIONS

- In collaboration with tribal health programs and cancer survivors, develop and implement a comprehensive cancer control education program.
- Integration of a cancer prevention message (i.e. lifestyle changes – diet and exercise) within existing tribal health programs – diabetes, wellness, tobacco and elder’s program. This would be cost effective in terms of staff time, but would also utilize an effective prevention focus emphasizing behavioral change in establishing a healthy diet and active lifestyle in the prevention of diabetes and cancer.
- Enhance education, possibly through services provided at the Tribal Health Center, regarding types/recommended annual screening; financial/insurance information; available support services for cancer survivors and their families. The interview participants indicated that they had a limited knowledge of: the types of available cancer screening; information about the need for types of annual screening; what was the appropriate age to begin specific cancer screening; as well as, how the expense of the screening be paid (i.e. IHS, tribal insurance, private insurance, etc.).
- To address the specific environmental causes identified by community members:

- ⇒ Specific outreach through the elders' program in the provision of education and information regarding recommended cancer screening and support.
- ⇒ Contact the Superfund Basic Research Program (SBRP) at a state university regarding whether there is the possibility of collaborating with the tribe to assess if they are at risk to any potential hazardous waste exposure in the community and next steps.
- ⇒ Review potential need to develop, implement and evaluate tribal environmental policy specific to air pollutants and toxic waste exposure, as well as potential remediation options.
- ⇒ Review and enhance, as appropriate, any existing tribal environmental policy specific to air pollutants and toxic waste exposure and remediation options.

Based on the interview results, there is a clearly a need for the development of a comprehensive cancer education program. It would need to include education specific to: risk factors, cancer screening information, treatment information, information and availability of cancer clinical trials, financial/insurance information specific to cancer services, available support services for cancer survivors and their families, and information about palliative and hospice care.

SUMMARY

The research aim and questions for this study originated from the community. The shared voices and lived experience provided the content, structure, and meaning of the shared cultural model that existed. The significance of utilizing a community-based participatory research (CBPR) approach cannot be overemphasized in developing meaningful partnerships in American Indian and Alaska Native communities that address the current health disparities that are important to the health and well-being of their members. The resulting outcomes and data will provide the means for the community to take next steps in developing health education, risk reduction and treatment services that are cultural responsive to their identified needs and enhance a new expression of self-determination in research to address health disparities.

Data Collection

Data Analysis

