

The Shared Cultural Knowledge and Beliefs about Cancer
in the Yavapai-Apache Community

by

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ABSTRACT

Native American communities face an ongoing challenge of effectively addressing cancer health disparities, as well as environmental racism issues that may compound these inequities. This dissertation identified the shared cultural knowledge and beliefs about cancer in a southwest American Indian community utilizing a cultural consensus method, an approach that combines qualitative and quantitative data. A community-based participatory research (CBPR) approach was applied at all stages of the study.

The three phases of research that were undertaken included: 1) ethnographic interviews – to identifying the themes or the content of the participants' cultural model, 2A) ranking of themes – to provide an understanding of the relative importance of the content of the cultural model, 2B) pile sorts – identify the organization of items within specific domains, and 3) a community survey – assess whether the model is shared in the greater community.

The cultural consensus method has not been utilized to date in identifying the collective cultural beliefs about cancer prevention, treatment or survivorship in a Native American community. Its use represents a methodological step forward in two areas: 1) the traditional ethnographic inferences used in identifying and defining cultural meaning as it relates to health can be tested more rigorously than in the past, and 2) it addresses the challenge of providing reliable results based on a small

number of community informants. This is especially significant when working with smaller tribal/cultural groups where the small sample size has led to questions concerning the reliability and validity of health-related research.

Results showed that the key consultants shared strong agreement or consensus on a cultural model regarding the importance of environmental and lifestyle causes of cancer. However, there was no consensus found among the key consultants on the prevention and treatment of cancer. The results of the community survey indicated agreement or consensus in the sub-domains of descriptions of cancer, risk/cause, prevention, treatment, remission/cure and living with cancer.

Identifying cultural beliefs and models regarding cancer could contribute to the effective development of culturally responsive cancer prevention education and treatment programs.

DEDICATION

To my family

Dad and Mom, Adam and Spencer, Sharolyn,
Huron and Lois, Sonny and Pearl, Rei Lyn and Cecil,
Dan and Melissa, Hannah and Hudson
whose love, encouragement, support, and faithful prayers
have made it possible for me to complete this long journey.
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CHAPTER 1

INTRODUCTION

What are the cultural beliefs that may influence the response of a community to illness and disease? How can shared cultural knowledge regarding illness and disease be described and measured?

Anthropologists have long had an interest in studying and recording ways in which different cultures deal with, think about, and integrate disease into their wider systems of beliefs, values and behaviors. This interest is now receiving greater visibility with an increased awareness of and priority in understanding and addressing the impact of health disparities within Native American communities in the United States.

The goal of the research study was to determine if a cultural model of cancer existed in the Yavapai-Apache community located in the Verde Valley in central Arizona. A community-based participatory research (CBPR) approach was utilized when applying a cultural consensus method in identifying the collective knowledge and beliefs about the prevention, cause(s), treatment, and survivorship of cancer.

The specific aims of the research were to answer the following questions:

1. What are the community members' knowledge and beliefs about cancer?
2. Do they believe it can be prevented?

3. Is there cultural consensus in the community regarding the cause(s) of cancer?
4. Do they believe it can be effectively treated or cured?
5. What do they believe are reasons a person continues to live even after they are told they have cancer?

Three phases of research were undertaken: 1) ethnographic interviews – identifying themes or the content of the participants' cultural model, 2A) ranking of themes – understanding the relative importance of the content of the cultural model, 2B) pile sorts – the organization of items within specific domains, and 3) a community survey – whether the model is shared in the greater community.

The cultural consensus method has not been utilized to date in identifying the collective cultural beliefs about cancer prevention, treatment or survivorship in a Native American community. Its use represents a methodological step forward in two areas.

First, the traditional ethnographic inferences used in identifying and defining cultural meaning as it relates to health can be tested more rigorously than in the past. A second significant contribution of this method is that it addresses the challenge of providing reliable results based on a small number of community informants, thereby avoiding the necessity of acquiring large sample sizes to objectively ensure the confidence of the responses provided. This is especially significant when working with smaller AI/AN tribal/cultural groups where the small sample

size has led to questions concerning the reliability and validity of health-related research.

A recently completed study by the University of California-Davis, found that the high death rates from breast cancer in American Indian and Alaska Native women were linked to cultural beliefs, not barriers such as poor access to health care (UC-Davis, 2011). This highlights the critical importance of identifying the cultural beliefs about cancer within tribal communities. The results of this project will contribute to the broader knowledge and development of new approaches in implementing culturally responsive cancer prevention and control strategies that incorporate the explanatory models of tribal communities.

Understanding Yavapai-Apache cultural beliefs regarding cancer could potentially contribute to the development of a more culturally responsive cancer prevention education program that increases the frequency with which tribal members seek preventive cancer education and screening.

Overview of the Chapters

Chapter 2 of the dissertation, “The Challenge of Addressing Health Disparities,” provides an overview of the current disparate health status of experienced by minority/ethnic populations in the United States. Following this introduction, a historic perspective of health disparities in American Indian/Alaska Native (AI/AN) is presented, and continues to the current health conditions of communities with a review of the literature of the more

recent experience of cancer in Native communities. Additionally, a historic overview of the environmental justice movement that developed in response to the experience of environmental racism perpetrated in racial and ethnic communities is provided, including the unique perspective of AI/AN communities and the role of tribal sovereignty and self-governance. The chapter closes with a focus on the important role of a community-based participatory research (CBPR) approach in successfully working in partnership with tribal communities in addressing health disparities.

Chapter 3 provides a comprehensive historic overview of the background of the Yavapai-Apache community and the historical challenges to the survival of their cultural community. The current health challenges are also reviewed and the steps the tribe is taking to address their community health needs.

Chapter 4 describes the theory and methods used in this research study in applying a cultural consensus model in the analysis of culture. A detailed description is also provided regarding the study site, required research approvals; and the three phases of the research model used in the implementation of the study;

Chapter 5 presents the analysis and results of the ethnographic interviews completed in the community and the identification of the themes of the domain of cancer.

Chapter 6 presents the cultural consensus analysis data and results used in determining the existence of a cultural model specific to the

prevention, cause and treatment of cancer from rankings, pile sorts and a community-wide survey.

Chapter 7 presents a discussion on the answers to the research questions based on the data results from the ethnographic interviews, rankings, pile sorts, and community-wide survey. The limitations of the study are provided, possible implications to tribal environmental policy, recommendations for programmatic development and enhancement of health services, as well as potential next steps in research identified by the community.

CHAPTER 2

THE CHALLENGE OF ADDRESSING HEALTH DISPARITIES

Health Disparities in the United States

The causes of health disparities and why minority/ethnic populations are overburdened with disease and poor health outcomes are now the focus of research in government agencies, universities, and communities. There are several terms utilized to define and describe this current status, all with a focus in increasing an understanding of applying methods and approaches to further the goal of the reduction or elimination of inequities of health for all communities.

Healthy People 2010 (DHHS, 2000) defines disparities in *health* as the “unequal burden in disease morbidity and mortality rates experienced by ethnic/racial groups as compared to the dominant group”. The Institute of Medicine’s 2002 report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* (the IOM Report) defines disparities in *health care* as “differences in the quality of health care that are not due to access-related factors or clinical needs, preferences or appropriateness of intervention (Smedley, Stith, & Nelson, 2003, p. 3, 4). The Health Resources and Services Administration, a key player in the national effort to eliminate disparities in health, defines health disparities as population-specific differences in the presence of disease, health outcomes, or access to health care (HRSA, 2000).

Are there promising solutions to this complex problem? A recent review of the research literature suggests that a multitude of complex factors contributes to health disparities, but little is known about the relative importance or influence of these factors.

In the 1985 Health and Human *Services' Report of the Secretary's Task Force on Black and Minority Health*, health is said to be influenced by interaction of physiological, cultural, psychological, and societal factors that are poorly understood for the general population and even less for minorities (Heckler, 1985). In short, it is challenging for social scientists, including anthropologists, to find ways to determine if, how and to what extent each of these factors is related to health disparities experienced by ethnic/cultural communities. When there is an increased understanding about what specific factors play a key role in contributing to the disparate health status of minority/ethnic populations then appropriate advances can be taken and applied in reducing or eliminating these challenges, especially among those communities so severely affected.

Health Disparities among American Indians and Alaska Natives

The U.S. Census (Ogunwole, 2002; Stoffel, 2006) indicated that 4.3 million (1.5%) adults in the United States identified themselves as American Indian and Alaska Native (AI/AN). Approximately half (2.4 million) of that population indicated they are of one race or ethnicity, while the remaining 44% indicated they were AI/AN in combination with one or more other races. The AI/AN population is comprised of 565 federally

recognized tribes, as well as a number of other tribes that are not federally recognized. According to the 2000 census, 42% of the AI/AN population lived in the West, 31% lived in the South, 17% lived in the Midwest, and 9% lived in the Northeast. The report also showed that 57% resides in urban areas, with the remaining 43% living in rural or reservation areas.

The Indian Health Care System

Federal health services for AI/AN began in the early 19th century. Since the first treaties of 1784, the federal government acknowledged the responsibility of health care for Native Americans. This responsibility expanded into medical care in the 1830s, when Army physicians took steps to curb smallpox and other contagious diseases among tribes living in the vicinity of military posts. At that time, the federal government entered into a new series of treaties. They agreed to provide medical care in return for rights and property ceded to the government. Bureau medical personnel began treating reservation diseases that had been created by the social and economic conditions essentially produced by the Bureau's policies. The role of reservation medicine therefore was never separate from the political policy of assimilation (Campbell, 1989). The extent of medical assistance, however, was surveillance rather than any healthful service. For example, hospitals were not constructed to isolate infectious Indian people or to provide a sanitary location to perform medical services, but were constructed to civilize sick Indian people away from tribal

influences. Needless to say, ill health continued into the mid-twentieth century (Campbell 1989).

For more than 120 years, the responsibility of health care passed among different government branches. In 1955, it was officially transferred from the Department of Interior and the Bureau of Indian Affairs to the Public Health Service (PHS) under P.L. 83-568, the Transfer Act, which created the Indian Health Service (IHS) (Kunitz, 1996; Prucha, 1986). This Act provided “that all functions, responsibilities, authorities, and duties. . .relating to the maintenance and operation of hospital and health facilities for Indians, and the conservation of Indian health. . .shall be administered by the Surgeon General of the United States Public Health Service” (Prucha, 1994; IHS, 2009). The result of the transfer was to create the only National Health Service for civilians in the United States, one that provided nearly the full range of public and personal services to a defined population. Many Indians and non-Indians, in the 40 years since the transfer, have come to see the program as an entitlement, something owed to Indians as a result of treaty rights and trust obligations. However, the level and distribution of services are shaped by annual discretionary appropriations (Kunitz, 1996).

For many years the Indian Health Service (IHS) was the primary source of health care for American Indians and Alaska Natives. However, due to changes in legislation and policy to address the health needs of the population, the Indian health care system presently consists of three major

types of health programs. Members of 565 federal recognized AI/AN Tribes obtain health care for their members from the federal government through, 1) direct services, 2) contracts, and compacts, or 3) Urban Indian Health Programs. Specifically, Tribes can choose to receive health care services:

1. Directly from the Indian Health Service (IHS) - A number of tribes have selected to have the Federal Government continue to provide health services to their people and represent 65 percent of the IHS annual budget. When a tribe elects this option, the IHS provides a range of services that may include hospital and outpatient care, preventive and rehabilitative services, and the development and maintenance of health-related community infrastructures such as sewage treatment facilities. Although the IHS continues to provide health services in many American Indian and Alaska Native communities, the agency works closely with local tribal leaders to plan needed services (IHS, 2009).

Patients access this system of 28 hospitals (ranging in size from 11 to 170 beds per hospital, including medical centers in Phoenix, Arizona and Gallup, New Mexico), 63 health centers and 31 health stations on or near reservations for direct health care services, or are referred to non-IHS providers for specialty care under the Contract Health Services program if they meet eligibility requirements. The IHS currently serves approximately 2 million

AI/AN Natives. Its fiscal year 2010 appropriated budget totaled approximately \$4.05 billion. For 55 percent of Indians, the service is the sole provider of care. Seventeen percent also have other public coverage such as Medicaid or Medicare. An additional 28 percent have private health insurance.

2. Tribal Health Programs: a) Contract with the IHS to administer individual programs and services the IHS would otherwise provide (referred to as Title I Self-Determination Contracts); and b) compact with the IHS to assume control over health care programs the IHS would otherwise provide (referred to as Title IV Self-Governance Compacts). The Indian Self-Determination and educational Assistance Act of 1975 (P.L. 93-638) allows federally recognized tribes to *contract* with the federal government to assume management of part or all of their health care programs (Title I). And since the amendments to P.L. 93-638 in 1988, tribes can *compact* with the federal government to assume more independence in the management of their health programs (Title III) (IHS, 2009). In May 2002, the Department of Health and Human Services enacted final regulations to make the self-governance compacting demonstration project a permanent option for most IHS programs and activities, as it is for Department of Interior programs. Tribes are also advocating that opportunities to compact for IHS programs be extended beyond the IHS and encompass the entire

HHS. The IHS is actively supporting the tribes' efforts in this endeavor.

As of December 2010, the IHS has negotiated 78 self-governance compacts and 100 annual funding agreements with 332 Tribes and tribal organizations. This constitutes approximately \$1.4 billion of the IHS budget. These tribal Self-Governance programs serve 37 percent of total IHS users.

3. Urban Indian Health Programs – Currently 34 Urban Indian Programs receive federal funding under Title V of the Indian Health Care Improvement Act to provide health care services for American Indians and Alaska Natives who reside in urban areas and who meet eligibility requirements. Even though estimates indicate that over half of the American Indian population in the country lives in urban areas, less than one percent of the Indian Health Service budget is dedicated to urban Indian health programs. The services provided in these programs are heavily dependent on other sources of funding, such as Medicaid reimbursement, grants, and contracts (IHS, 2009).
4. Other Sources of Health Care – American Indians and Alaska Natives may be eligible for other sources of health care based on their income, work records, health status, ability to purchase private insurance, or tribal/community resources. These include: Medicaid, State Child Health Insurance Program (SCHIP),

Medicare, private insurance/managed care and traditional Indian medicine.

Tribes may choose to combine these options based on their individual needs and circumstances. Self-Governance compacting provides Tribes the most flexibility to tailor health care services to the needs of their communities.

Mortality trends for American Indians and Alaska Natives have changed dramatically since the 1950s when the Indian Health Service (IHS) became part of the Public Health Service. Substantial decreases in overall mortality rates have been documented, along with a shift in disease patterns from infectious diseases to chronic diseases. The epidemiological transition from infectious diseases has been credited to aggressive public health programs to improve sanitation, increase immunizations, as well as the other contributors such as the introduction of antibiotics (Rhoades, D'Angelo, Hurlburt, 1987). The current shift to mortality caused by several chronic conditions (i.e. diabetes, cancer, heart disease) has often been attributed to changes in diet and exercise patterns and increased availability of processed foods (Kunitz, 2008). Although the improvements in health have been substantial in such a short length of time, disparities or inequalities between American Indians and the U.S. general population still remain (Wosley & Cheek, 1999).

The report "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care" has stated that even today, Native people have

low life-expectancy rates and continue to suffer from diseases typically experienced by older populations. Native American death rates for diabetes, alcoholism, suicide and accidents are greater than all other races and ethnic groups. The report states, "The U.S. government is obligated through treaty and federal statute to provide healthcare to members of federally recognized American Indian tribes," and further states, "This trust, however, has not been fully met, for several reasons." (Smedley, et al., 2003, p. 85). The report confirmed for many the substandard services provided in Indian Country. Access to services is limited both on and off the reservation, and healthcare spending is below the stated need.

In 2000, Dr. Michael Trujillo, the Director of the IHS, attributed health disparities for American Indians/Alaska Natives to a number of underlying causes, including social and cultural disruption of tribal societies, poor education, longstanding poverty, lack of political presence, limited access to health services, and a widening gap in health care spending (Trujillo, 2000). The spending gap for health care is especially telling when the IHS per capita spending for healthcare is compared with other federal programs. The IHS annual per capita healthcare spending (medical care) in 2010 per user was \$2,741, far less than that for the general U.S. population at \$5,711. This IHS per capita spending is also substantially lower than that for Medicare spending per beneficiary (\$11,018); Medicaid per enrollee (\$5,841), Bureau of Prisons (\$4,333 in

2003); and Veterans' Administration per user (\$7,154), or the Federal Employee Health Benefits per enrollee (\$4,817) (National Indian Health Board, 2011). As previously mentioned, for fiscal year 2010 the IHS appropriated budget totaled approximately \$4.05 billion, however, it is estimated that to fully fund the IHS' total need would be \$22.1 billion (NIHB, 2011).

Researchers examining medical care expenditures have underscored the lack of health coverage. They found that only one in three AI/AN people interviewed had private health insurance, compared with 80 percent of whites, 52 percent of African Americans, and 50 percent of Hispanics. Over 55% of AI/AN patients rely on IHS as the only source of health care coverage. Only 25% had employment-related insurance, and 17% had other public coverage. For those American Indians and Alaska Natives with private health insurance, there are also problems, as researchers found. Prejudice, cultural barriers, and limits by health plans are among the factors contributing to treatment that is unequal to that received by white Americans (Smedley, et. al, 2003).

Although there are significant existing differences in morbidity and mortality trends among tribes in different geographic areas, many overall similarities remain. According to the Centers for Disease Control, National Health Statistics Report (Barnes, Adams, and Powell-Griner, 2010), Native Americans have extremely high rates of diabetes, infant mortality, certain sexually transmitted diseases, unintentional injuries, and motor vehicle

accidents. In almost every case, the rate among Native Americans not only surpassed that of whites, but also of other minority groups.

- Chronic diseases – Heart disease and cancer are the leading causes of death for Native Americans. The prevalence of diabetes (16.5%) is more than twice that for all adults in the United States, and it continues to increase. The mortality rate from chronic liver disease and cirrhosis is more than twice as high, and the sixth leading cause of death. (Acton, Burrows, Geiss, & Thompson, 2003; Paisano, Cobb, & Espey, 2003; IHS, 2011)
- Infant Mortality – The infant mortality rate is 1.7 times higher than non-Hispanic whites. The sudden infant death syndrome (SIDS) rate is the highest in the nation, more than double that of whites in 1999. (Wood, Santibanez, Barker, & Singleton, 2003; IHS, 2011)
- Sexually transmitted diseases (STDs) – In 2001, the syphilis rate was 6 times higher than the rate among the non-Hispanic white population, the Chlamydia rate was 5.5 times higher, the gonorrhea rate was 4 times higher and the AIDS rate was 1.5 times higher. (IHS, 2011)
- Injuries – Unintentional injuries are the third leading cause of death and the leading cause for Natives aged 1-44 years. In 2005, death rates for unintentional injuries and motor vehicle crashes accounted for more than twice the percentage of deaths (11.7%) of the AI/AN compared with other population groups combined, while age adjusted suicide rates were 1.73 times as high as the corresponding rates for all persons combined. The suicide rates among Native youth are 3 times greater than rates for whites of similar age. (Wallace, 2003; IHS, 2011)
- Mortality – AI/AN die at higher rates than other Americans from tuberculosis (500% higher), alcoholism (514% higher), diabetes (177% higher), and homicide (92% higher). (IHS, 2011)
- Life Expectancy – the AI/AN population has a life expectancy at birth that is 5.2 years less than that for all U.S. populations

combined, and have 1.2 times as many years of potential life lost at age 75 as that of all other populations combined. (IHS, 2011)

It has been noted that patterns of morbidity and mortality among American Indians and Alaskan Natives are similar to those seen in other indigenous populations throughout the world. For example, the indigenous populations of Australia have death rates that are two to eight times higher compared to non-Aboriginal rates. They also experience growing numbers of non-communicable diseases, particularly cardiovascular disease and diabetes, although there has been little decline in rates of infectious disease morbidity. Similar to American Indians and Alaskan Natives, Aborigines experience high rates of diabetes, with 30% of the adult population diagnosed with the disease (Bhatia and Anderson, 1995). The similarities in health status between two indigenous populations undoubtedly reflect similarities in the drastic changes both groups have experienced in relationship to dominant cultures much different from their traditional past.

Today, a complex mixture of social and political issues, including poverty, unemployment, diet and lifestyle, affects American Indian and Alaskan Native health. Continued declines in morbidity and mortality rates will no longer be attained by vaccinations and medications, but must include addressing larger social policy issues from a systematic view that would provide the basis for the development of programs and services that could lead to sustained positive changes.

Cancer Health Disparities in American Indian and Alaska Native Communities

The National Cancer Institute (NCI) established the Center to Reduce Cancer Health Disparities in 2001 in order to address cancer health disparities across the cancer control continuum from disease prevention to end-of-life care. Many ethnic minority groups develop cancer more frequently than the majority white population. Some specific forms of cancer affect ethnic minority communities at rates up to several times higher than national averages. Many ethnic minority groups also experience poorer survival rates.

Cancer rates, which were previously reported to be lower in American Indians and Alaska Natives (AI/AN), have increased in the past twenty years. Cancer is now the second leading cause of death among AI/AN throughout the country (Paisano, Cobb, & Espey, 2003; Department of Health and Human Services, 2000). The age adjusted mortality rate for nine Indian Health Service regions is calculated at 148.2/100,000. The types of cancer experienced within Native communities vary significantly by geographic region, indicating that specific cancer data for one region cannot be used to generalize to AI/AN living in another part of the country (Burhansstipanov, Gilbert, LaMarca, & Krebs, 2001; Paisano et al., 2003; Department of Health and Human Services, 2000). This may suggest differences in environmental exposure, behavioral and/or cultural practices.

Cancer Surveillance Data

Data on cancer among AI/AN continues to be challenging for a number of reasons, some of them related to issues of ethnic/racial definition, diversity across tribes and regions, and the numbers of AI living in different regions making it difficult to collect aggregate data on cancer incidence. Previous publications have relied on mortality data from death certificates or have reported on incidence in limited areas covered by state or local cancer surveillance systems, primarily those in the Surveillance, Epidemiology, and End Results (SEER) cancer registry system (Cobb, Wingo, Edwards, 2008).

The National Cancer Institute (NCI) has funded and supported the SEER Program since 1973. SEER routinely collects data on patient demographics, primary tumor site, tumor morphology and stage of diagnosis. Recognizing the importance of understanding cancer patterns in minority populations, NCI provides data for AIs in Arizona and New Mexico and ANs in the SEER System, and more recently has begun to develop tribally-based cancer registries at the Cherokee Nation of Oklahoma and in the Northwest. SEER registries currently cover 26% of the total US population, including 42% of AI/AN (Cobb et al., 2008). The cancer data from these sources has shown that ANs have rates of lung, colon, and breast cancer 5 times higher than those of Southwestern Indians, whereas rates of stomach, kidney, uterine, cervix, and liver

cancer are similar in the 2 regions, and higher than in non-Hispanic whites (NHW) (Cobb et al., 2008).

Studies using death certificates (Epsey, Paisano, Cobb, 2005) and IHS hospital data (Nutting, Freeman, Risser, et al. 1993) indicated that cancer rates in the Northern Plains and other regions were as high as in Alaska. However, population-based cancer incidence data were not available for AIs outside of the southwest until recently (Cobb et al., 2008).

There is, however, no single national database that accurately presents comprehensive cancer data for AI/ANs. In the past, few central cancer registries were concerned about correctly identifying AI/AN in their databases, where race and ethnicity were abstracted from medical records. Numerous studies have demonstrated that many AI/ANs were misclassified as another race in cancer registry data and that the extent of misclassification varied by registry (Cobb et al., 2008). When coupled with population denominators from the US Census Bureau, where race is self-identified, this had the effect of lowering apparent cancer rates for AI/AN (Burhannstipanov and Dresser, 1994; Burhansstipanov et al., 2001).

Recent studies have shown that there is a 40-50% misclassification of AI as either White or Hispanic. (Hampton and Henderson, 1999) Misclassification is primarily due to: a) use of Spanish surnames to determine race, b) personal observation by data collectors to determine race; c) lack of AI/AN response category on forms, d) inconsistent definitions of AI/AN, and e) federal recognition of tribal Nations in addition

to state-recognition (i.e. a non-federally recognized tribal member may not identify as AI/AN). (Burhansstipanov et al., 2001)

A recent collaborative study that included the IHS, NCI, CDC and all National Program of Cancer Registries (NPCR) and SEER cancer registries completed a linkage of IHS beneficiary records with their respective cancer registry databases. Linkages to identify AI/AN cases misclassified as non-Native were conducted using a software program developed by the CDC that identified records representing the same individual in IHS and cancer registry databases. Analyses focused on cases among AI/AN residents in IHS Contract Health Service Delivery Area (CHSDA) counties in 33 states. Cancer incidence and stage data were compiled for NHWs and AI/ANs across 6 IHS regions of the U.S. for 1999 through 2004. The results indicated misclassification of AI/AN race as non-Native in central cancer registries ranging from 85 individuals in Alaska (3.4%) to 5,297 individuals in the Southern Plains (44.5%) (Epsey, Wiggins, Jim, et al., 2008). Cancer incidence rates among AI/ANs for all cancer combined were lower than for NHWs, but incidence rates varied by geographic regions for AI/ANs (Epsey, Wiggins, Jim et al., 2008).

National Cancer Rates

At the beginning of the 20th century, AI/AN were said to never have cancer. (Hampton, 1992) Initial data accumulated under the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program indicated a lower incidence of cancer in the AI/AN population

than in the U.S. as a whole (Hampton, 1992). However, SEER data were derived from only a limited AI/AN population. However, even in this small sampling, survival rates were lower than for the general U.S. population. The five-year relative survival for “all sites combined” for AI/ANs is 35.2%, which is the poorest survival from cancer of any population group (Boss, 1986; Department of Health and Human Services, 2009). Part of the reason for the high mortality is that AI/ANs are more likely not to be diagnosed until the cancer is at an advanced stage (Mahoney & Michalek, 1991; Department of Health and Human Services, 2009). The poor cancer survival rates for Native women have also been attributed to fear of cancer which has influenced a delay in seeking appropriate treatment, cultural beliefs, and underutilization of available treatment options (Braun, Look, & Sark, 1995; Department of Health and Human Services, 2000; Horner, 1990).

Wilson-Taylor’s study on quality of breast cancer care for women living in New Mexico found significant disparities in time to first cancer-directed surgery for AI women for every interval examined, compared to non-Hispanic White women. Controlling for age, stage, grade and census-tract poverty-level, AI women were four times more likely to receive their first cancer directed surgery more than six months (186 days) after diagnosis (Wilson, 2007).

Additionally, because cancer patients often are treated in non-IHS facilities, there are few critical data on incidence, treatment modalities,

follow-up outcomes, complications, and compliance. Consequently, the types of cancers and the number of tribes studied frequently limit what is known about cancer and cancer risks for AIs (Justice, 1988; Mahoney & Michalek, 1991).

Cancer Rates in Arizona

Cancer is a major public health problem in Arizona. It is estimated that 23,560 individuals will be diagnosed with cancer this year. It is the second leading cause of death in Arizona, second only to heart disease. Similar to the U.S., four cancer sites account for more than half of Arizona's cancer burden. These include breast, colon and rectum, lung and bronchus, and prostate cancers. Although these cancer sites account for the majority of cancer burden among adults in Arizona and the U.S., variations in leading sites are seen due to gender, race/ethnicity and age differences (American Cancer Society, 2004).

The five most commonly diagnosed cancers among Arizona AI males (n=138) are prostate (21%), colon and rectum (10%), kidney/RP (9%), lung and bronchus (7%) and stomach (6%). Among AI females (n=166) it includes breast (24%), uterus (8%), colon and rectum (7%), ovary (7%), and kidney/RP (6%) (ACS, 2004).

The five leading cancer deaths among AI males (n=79) are liver (10%), lung (10%), prostate (10%) stomach (9%), and colon and rectum (8%). Among AI females (n=80) it includes breast (11%), ovary (7%), liver (6%), colon and rectum (6%), and lung (6%) (ACS, 2004).

A chart audit conducted at the Phoenix Indian Medical Center (1997-2001) indicated that the five most commonly treated cancer cases were: breast (20%), uterine/cervix (19%), skin (15%), and colon and rectum (10%).

In 2002, 56% of Arizona women age 40 and older reported having had a mammogram and clinical breast exam (CBE) in the past year. As in other areas of the nation, differences in screening behaviors in Arizona are seen among women of different age, race and socioeconomic status. Hispanic women and those in the "Other" category (which includes American Indian and Asian/Pacific Islander) have lower screening rates than White, non-Hispanic women, for mammogram and clinical breast examinations (Arizona Department of Health Services, 2005).

Although breast cancer is a diagnosis that many are able to survive, screening, diagnosis, and treatment are often characterized by disparities in experiences and outcomes (Hampton, 1988). Nationally, deaths from breast cancer occur disproportionately among women of different racial, ethnic, and socioeconomic backgrounds.

Studies show that early detection of breast cancer can save lives. Therefore, many breast cancer deaths could be avoided by increasing cancer screening rates among women at risk. Timely mammography, every 1-2 years for women aged 40 years and older, can reduce mortality by approximately 20-25% over 10 years (Freeman & Wingrove, 2005).

Although the breast cancer screening rate for the general U.S. population is about 70%, according to the 2000 National Health Interview Survey (CDC, 2002), the breast cancer screening rate is 71% for white women, 68% for African American women, 61% for Hispanic and Latino women, 59% for Asian women, and 52% for AI/AN women. Breast cancer is the most frequently diagnosed cancer among Arizona women across all races/ethnicities for which data is available. It is the primary cause of cancer mortality among Native American women (ADHS, 2005). As in other areas of the nation, differences in screening behaviors in Arizona are seen among women of different age, race and socioeconomic status. (Freeman & Wingrove, 2005).

Cervical cancer is one of the most preventable and treatable cancers with a five-year survival of 99% if detected at an early stage (Schiffman and Hildeshiem, 2006). The importance of being screened regularly for cervical cancer cannot be underestimated in that once detected at a regional or distant stage (Stage III or IV), the cervical cancer survival rate is estimated at 10% or less (Perez, Kurman, Stehman, & Thigpen, 1992).

A recent report from the National Cancer Institute (NCI) indicates that there is strong evidence to indicate that Northern Plains Indians and Alaska Native women have higher rates of death due to cervical cancer than white women (3.4 deaths per 100,000) (Freeman & Wingrove, 2005). In Arizona, Hispanic and Native American women exhibit the first and

second highest cervical cancer incidence rates, but Native American and African American women experience the greatest mortality (ADHS, 2005).

More than half (53%) of the colorectal cancers diagnosed in Arizona between 1995 and 2000 were detected in late (regional and distant) stages. Over half of the colorectal cancers are diagnosed in late stage for all of Arizona's racial groups, with the exception of Asian/Pacific Islanders (ACS, 2004).

In 2002, 23% of adults in Arizona reported being current smokers. Among racial/ethnic groups, Hispanics have the lowest smoking prevalence (18%), compared to those in the "Other" category (30%), which includes AIs. Over two-thirds of lung cancers are diagnosed in late stage for American Indians (ACS, 2004).

Anthropology's contribution to cancer control has been especially dominant in the development of cultural models of disease (explanatory models), and in describing ideas about cancer and its prevention and to explain participation in screening and other prevention programs. Additionally, an understanding of the meanings and impact of cancer has been advanced by narrative approaches as explored in the works of Kleinman (1988) and Good (1994).

Unfortunately, there are very few anthropological studies that have been completed in Native American communities specifically identifying explanatory models related to cancer and its meaning to Native people. Very little is known about AI/AN attitudes or knowledge about cancer.

Anecdotally, cancer has been described in some communities as a White man's disease, or as a fatal disease (Joe, 2003; Weiner, 1993). Among the Yup'ik Eskimos and the Navajos, cancer is referred to as a sore that does not heal, a perception that would seem to enforce a fatalistic attitude toward cancer (Joe, 2003).

In some tribal communities there is an avoidance of talking about prevention or screening for cancer because of the power of words, i.e., talking about cancer may cause the illness to happen. This belief, although not frequently verbalized openly, prevents individuals from discussing cancer in public or encouraging others to respond to preventive message or action. (Joe, 2003)

One of the American Cancer Society's three goals for 2015 (ACS, 2005) is to measurably improve the quality of life (QOL) of all cancer survivors, family members and caregivers from the time of diagnosis and for the balance of life. The essence of one's quality of life, regardless of the status of life or state of health, is the individual's capability to make personal, meaningful decisions that satisfy one's innermost needs.

It has been noted that of the numerous articles written between 1990 and 1995 that were noted in the Quality of Life Literature Database, none included references to Native American cancer survivors (Burhansstipanov et al., 2001). Additionally, minority cancer survivors, the elderly, and the poor are the least studied (Curbow, 1997). The few references on cancer in minority populations tend to focus primarily on

newly diagnosed patients rather than on long-term cancer survivors, with particular emphasis on breast cancer survivors (Burhansstipanov et al., 2001).

There have been no comparative studies or data to answer questions such as whether Native populations have the same quality of life (QOL) concerns and outcomes as cancer survivors in the general population. As a result, the National Cancer Institute (NCI) has recently confirmed the need to assess QOL in culturally diverse populations of cancer survivors (Varricchio, McCabe, & Tribble, 1996).

The publications that are available and have included AI/AN cancer survivors note the challenges faced by many with regard to their access to quality care (Burhansstipanov et al., 2001; Kaur, 1995, 1996; Lanier, et al., 1996). One study regarding Native American cancer survivors found that Native American breast cancer survivors were less likely to have breast-conserving surgery, and if it was performed, it was only possible outside the resources of the federal Indian Health Service (IHS), the primary health care provider for many of these women.

As a result of the tribal/cultural diversity among AI/ANs, it can be hypothesized that perceptions of cancer, treatment, and healing will differ. When asked, most AI/AN cancer survivors usually reported that they have participated in traditional and spiritual healing in conjunction with biomedical care for their cancer, and often live longer than their medical prognosis. The majority of these survivors also indicated that they value

the spiritual aspect of healing ceremonies. Cancer survivors view the inclusion or addition of tribal spiritual healing as a way to enhance cancer treatment and promote survival (Burhansstipanov et al., 2001).

As stated by an AI women diagnosed with breast cancer:

My oncologist and I agreed that radiation and chemotherapy were necessary, but the unsettling part of the prognosis is that even the experts could not guarantee that the cancer would not return. Relying on my tribal cultural strengths was especially helpful in facing some of these uncertainties, because the Navajo cultural context in dealing with illness is predominately spiritual. The cultural and spiritual resources made the 'unknowns' less threatening so that one can focus attention on getting well. This healing concept that emphasizes attention on 'getting well' is an inseparable part of my cultural heritage and is among the important cornerstones of my grandparents' understanding and approach to healing. (Joe, 1999; p.433).

Qualitative research utilizing grounded theory has been applied in a collaborative study with a Pacific Northwest Indian tribal communities to address attitudes about Papanicolaou (Pap) test screening in developing a more culturally appropriate intervention for improving screening rates among Yakama Indian women (Strickland, 1999).

The findings from the Yakama study indicated that the women viewed Pap tests as important during certain phases of the women's life course or her life's journey. This life's journey was conceptualized as walking the journey of womanhood and consisted of four phases, 1) starting the journey (adolescence), 2) blooming (becoming a woman), 3) heading the household (adult woman, married with family responsibilities), and 4) becoming an elder (Strickland, 1999). The women viewed the life

cycle as circular. One of the few research studies examining the process of cultural medication in cancer diagnosis and end of life decision-making, was implemented among First Nations patients in Canada (Kaufert, 1999). It summarizes interview and observational data on the experience of ten Canadians from First Nations communities who were receiving palliative care for renal cancers and other forms of end stage renal disease. Parallel interviews were also conducted with participants and their families, their health care providers and First Nations health interpreters. The study indicated that older informants and family members asserted cultural values prohibiting direct communication involving terminal prognosis or palliative care options. Kaufert states that their perspective appeared to reflect traditional prohibitions against telling bad news, as it related to the belief that using references or words related to death had the capacity to create reality (Kaufert, 1999). Younger Aboriginal informants were more likely to think that providers should be truthful about the individual's diagnosis and risk of dying, but they also criticized them for their insensitivity in telling bad news. The health interpreters who were interviewed emphasized the importance of bad news being communicated in a respectful manner and so as to allow time for the patient to absorb the message. They described an approach of beginning with less specific references to the disease and then only provided more explicit terminology as their own rapport with the patient developed and as the patient's family gathered and were available to provide support. The interpreters spoke of

the need to balance bad news with a message of hope and support (Kaufert, 1999). Kaufert indicates that Native leaders are becoming more vocal in their demands for change and for the provision of a system of palliative care congruent with First Nations values and priorities.

It has been suggested in scientific literature that lack of knowledge about the pathological or physiological process of cancer creates confusion and misunderstandings and results in lower screening rates. However, little is known about the potential conflict that cultural beliefs and/or meanings about cancer among Native Americans may impact prevention, screening, treatment options and end of life care.

Environmental Justice and Environmental Racism

What does “environmental justice” mean? What were the beginnings of the movement? And what impact has it had in addressing the exposure to environmental risks experienced by racial, ethnic and lower socioeconomic groups that could ultimately contribute to health disparities in these communities?

The environmental justice movement began as a grassroots response to evidence that indicated that environmental hazards disproportionately affect the health and well-being of low-income communities and communities of color, when compared to other groups. Sociologist Robert Bullard was a prominent figure and pivotal in documenting these inequities during the 1980s (Tsosie 2007).

Dr. Bullard has stated that the environmental justice movement began in 1982 in Warren County, North Carolina, where a polychlorinated biphenyl (PCB) landfill ignited protests and included over 500 arrests. [PCB is a toxic organic pollutant that has been demonstrated to cause cancer as well as a variety of other adverse health effects on the immune system, reproductive system, nervous system, and endocrine system (EPA, 2010). The protests provided the attention and momentum for a U.S. General Accounting Office (GAO, 1983) study, *Siting of Hazardous Waste Landfills and Their Correlation with Racial and Economic Status of Surrounding Communities*. The study revealed that three out of four of the off-site commercial hazardous waste landfills in Region 4 (which includes eight states in the South) happened to be located in predominately African-American communities, although African Americans made up only 20% of the region's population. Bullard states that "the protestors put environmental racism on the map" (Bullard 2000). Fifteen years later, the state of North Carolina was required to spend over \$25 million to clean up and detoxify the Warren County PCB landfill (Bullard 2001).

The Warren County protests also led to the ground-breaking national study conducted by the United Church of Christ's (UCC) Commission for Racial Justice, *Toxic Wastes and Race in the United States* (Goldman et al., 1994) which correlated waste facility sites and demographic characteristics. The study found that race was the most compelling variable in predicting where hazardous waste facilities were

located – more than poverty, land values, and home ownership. In 1990, *Dumping in Dixie: Race, Class, and Environmental Quality* (Bullard, 1990) recorded the union of two social movements – social justice and environmental movements into the environmental justice movement.

The 1991 First National People of Color Environmental Leadership Summit held in Washington, D.C. was considered one of the most important events in the movement's history. The summit broadened the scope of the environmental justice movement beyond its early antitoxics focus to now include issues of public health, worker safety, land use, transportation, housing, resource allocation, and community empowerment (Lee, 1992).

On September 27, 1991 summit delegates also adopted 17 “Principles of Environmental Justice,” to be used as a guide for organizing, networking, and relating to government and nongovernmental organizations (NGOs) (Bullard 2001).

By February 1994, in response to growing public concern and mounting scientific evidence, President Clinton issued Executive Order 12898, “Federal Actions to Address Environmental Justice in Minority Populations and Low-Income Populations” (1994). The Order attempted to address environmental injustice within existing federal laws and regulations (Bullard 2001). The Order also reinforced the 35-year old Civil Rights Act of 1964, Title VI, which prohibits discriminatory practices in programs receiving federal funds. Additionally, it brought focus back on

the National Environmental Policy Act (NEPA), a 25 year old law that set policy goals for the protection, maintenance, and enhancement of the environment. NEPA's goal is to ensure for all Americans a safe, healthful, productive, and aesthetically and culturally pleasing environment (1998). NEPA requires federal agencies to prepare a detailed statement on the environmental effects of proposed federal actions that significantly affect the quality of human health (Bullard 2001).

The Executive Order called for improved methodologies for assessing and mitigating impacts, health effects from multiple and cumulative exposure, collection of data on low-income and minority populations who may be disproportionately at risk, and impacts on subsistence fishers and wildlife consumers. It also encouraged participation of the impacted populations in the various phases of assessing impacts.

“Environmental racism” is a charge that was leveled by many communities of color as they developed their lines of defense in their neighborhoods. Dr. Benjamin F. Chavis, Jr., first called racial bias in the location of hazardous waste sites “environmental racism,” in the 1987 UCC study (Collins 1993). Scholars and activists have reached some agreement on the meaning of the term, and state that it is as real as the racism found in housing, employment, education and voting (Bullard 1993):

Environmental racism refers to any environmental policy, practice or directive that differentially affects or disadvantages (whether intended or unintended) individuals, groups, or communities based on race or color. Environmental racism is one form of environmental injustice and is reinforced by government, legal, economic, political, and military institutions. Environmental racism combines with public policies and industry practices to provide benefits for Whites while shifting costs to people of color (Bullard 2000, p. 559).

Environmental racism has been found to influence the likelihood of exposure to environmental and health risks as well as accessibility to health care (Colquette and Robertson 1991). Bullard has stated (2001) that many of the nation's environmental policies distribute the costs in a regressive pattern while providing disproportionate benefits for whites and individuals who fall at the upper end of the education, and income scale. Numerous studies have been cited, as far back as the seventies, that reveal that communities of color have borne greater health and environmental risk burdens than the society at large (Bullard and Feagin 1999). Elevated public health risks were found in some populations even when social class was held constant. Race was found to be independent of class in the distribution of air pollution (Mann, 1991), contaminated fish consumption (West et al. 1992), location of municipal landfill and incinerators (Bullard 1983), toxic waste dumps, cleanup of superfund sites (Mohai 1998), and lead poisoning of children (Lavelle and Coyle 1992).

In contrast, within the U.S. Environmental Protection Agency (EPA), the Office of Environmental Justice has defined the term "environmental justice " as follows:

The fair treatment and meaningful involvement of all people regardless of race, color, national origin, or income with respect to the development, implementation, and enforcement of environmental laws, regulations, and policies. Fair treatment means that no group of people, including racial, ethnic, or socioeconomic group should bear a disproportionate share of the negative environmental consequences resulting from industrial, municipal, and commercial operations or the execution of federal, state, local, and tribal programs and policies. (EPA, 2011)

The environmental justice movement came from a grass roots response to environmental inequities, threats to public health, unequal protection, differential enforcement, and unequal treatment received by the poor and people of color. The movement has redefined environmental protection as a basic right for all Americans without regard to race, color, national origin or income.

Environmental Justice and American Indian and Alaska Native Communities

It is ironic. The American Indians, who for so long have been maligned, mistreated and overlooked are emerging as the single largest private owners of energy resources (uranium, coal, oil, gas and geothermal) in this country. Certainly, when white men put Indians on reservations, they could not, in their wildest dreams have foreseen what this would mean to the Indian Nations. (Collins 1993, p. 290)

As extensive natural resources have begun to dwindle in the West over the past century, American Indian reservations have become appealing to the land and resource hunger of the United States marketplace. Reservation land covers over 56 million acres, or 3 percent of land in the continental United States, and is primarily rural and sparsely populated (McNally 1996). The federal government had little difficulty in

the removal of American Indians to what they considered wasteland in the nineteenth century. It must have been a surprise to the federal government when much of this land turned out to be rich with mineral deposits, as well as timber, grazing and agricultural land. It has been estimated that 25 percent of all of the nation's mineral wealth is located on reservation lands (Lester 1986).

As early as the 1900's when oil was discovered on Osage tribal land in Oklahoma, nonrenewable resource development has unleashed some of the most environmentally destructive forms of exploitation. Today, mine and drilling sites, roads and machinery, tailing piles, settling ponds, nuclear waste, nuclear testing and industrial pollution threaten tribal land, water, air, health and lifestyles. Due primarily to market pressure, a large percentage of reservation land is currently leased out to private, non-Indian interests. These interests (including the federal government) have dramatically overharvested the land through long-term leases often paying a fraction of the market worth (Wood 1994). Despite efforts by pan-Indian organizations like the Council of Energy Resource Tribes (CERT) to balance use and protection of resources, mining, oil and gas exploration has scarred thousands of acres with very little protection for residents (Ambler 1991).

A recent action to resolve a legal dispute that began when plaintiffs sued the Department of Interior in 1996 is the Claims Resolution Act of 2010 signed into law on December 8, 2010. The dispute was over the

Interior's alleged mismanagement of land accounts that had bilked American Indians out of billions of dollars since the accounts were created in 1887. The law includes a \$3.4 billion settlement for the 13-year-old legal battle (*Cobell v. Salazar*) over the Interior Department's mismanagement of land trust accounts and resources for American Indians. Included in the settlement are four water rights agreements, totaling more than \$1 billion, that will deliver clean drinking water to tribes in New Mexico, Arizona and Montana and will end decades of water allocation controversy among neighboring communities (Reis 2009; U.S. Department of the Interior 2010).

The discovery of large uranium deposits on reservation lands in the 1950's began a path of nuclear mining and milling that has left a legacy of nuclear waste and contamination across Indian country (Robinson 1992). It is estimated that over half of all uranium deposits in the United States are located on Indian reservations (Wood 1994). Because the land was legally held in trust by the federal government, it was the easiest and most economical for the government to mine (Wood 1994). As a result, almost all uranium mining occurred on Indian lands, and consequently tribal members became the obvious choice for a work force to staff the uranium mines (Johnson, 1993).

The southwestern section of the United States became the focal point of much of the history regarding uranium in its various forms. The Navajo and Hopi populations were victims of uranium mining operations

during the 1900s. The non-union miners were subjected to high levels of radiation, yet were given almost no protection against the known health hazards. One 1959 report found radiation levels ninety times above the acceptable limits (Lewis 1995). Numerous studies have provided evidence that Indian uranium miners suffered disproportionately from cancer and other uranium-related illnesses (Taliman 1994; Lucas 1989).

Extensive environmental destruction has marked their land and community, as more than 1,000 abandoned mines and tailing piles cover their reservations, exposing them to radioactive materials (LaDuke, 1999). The federal government initially allotted only \$750,000 over a three year period to clean up all these sites – or less than one percent of the actual estimated cost of an effective cleanup (Monson, 1982). Uranium mine waste pollutes groundwater, streams, and air (Churchill and LaDuke 1986). In 1979, a United Nuclear uranium mill tailings pond near Churchrock gave way, spilling its 100 million gallons of radioactive sludge into Rio Puerco River. Navajos still cannot use the water today (Lewis 1995). Cancers, respiratory ailments, and birth defects related to radiation exposure have impacted entire families and villages (Duncan 1992).

For Alaskan Natives, the effects of oil exploration multiplied under the 1971 Alaska Native Claims Settlement Act (ANCSA). The act ended Yup'ik, Inupiaq and Indian claims to aboriginal hunting, fishing and land rights on Alaska's 400 million acres, in return for 44 million acres of land and \$962.5 million to be administered for the 80,000 Alaskan Natives

through 200 village and regional corporations. The act was a mechanism for clearing access to Prudhoe Bay and North Slope oil reserves. Jobs and oil revenues are contributing to the escalating social changes in Alaskan villages, land and resource use patterns, diets and health, and attitudes toward subsistence and the environment (Anders, 1992). The massive oil spill by the Exxon Valdez was one of the first most public accidents affecting aquatic resources. (Lewis 1995).

American Indians and Alaska Natives face the potential degradation of their reservations from both on- and off-site polluters. In 1990, an estimated 1,200 hazardous waste sites were located on or adjacent to reservations. Cyanide heap-leach gold mining in Montana threatens the Sweetgrass Hills and is polluting water on the Fort Belknap Reservation (Bechle 1990); coal strip mines surround the Northern Cheyenne Reservation, disrupting the ground water (LaDuke 1992); heavy metals from a nearby tailing pond are showing up in vegetables on the San Xavier Reservation (Lakota Times, 1992); Acid rain and mercury from coal-fired power plants has affected the lakes of northern Minnesota, Wisconsin and Michigan, which are main sources of the wild rice, fish and waterfowl which are mainstays of the Anishnaabeg (Chippewa) diets (Morrison, 1994); industrial waste sites surround the St. Regis Mohawk Indian Reservation and contaminate the St. Lawrence River and the Akwesasne now sit directly next to a National Priority Superfund Site while two New York State Superfund sites are nearby and immediately upriver

(Schell, 2005); elevated levels of PCBs have been detected in the breast milk of nursing Mohawk mothers who consume fish or use water near the General Motors, Alcoa, and Reynolds plants (Tomsho 1990); in New Mexico a proposed asbestos dump on land next to the Navajo Reservation threatens air and water quality (Taliman 1994); and even noise pollution in the form of sonic booms from low-flying Air Force jets has become a factor in the life of the Shoshone-Paiute tribe of the Duck Valley Reservation in Nevada (Lewis, 1995).

Radioactive contamination has threatened a number of tribes far removed from the actual production of those materials. In 1951, the federal government and the Atomic Energy Commission set aside the Nevada Test Site (NTS) on Western Shoshone territory (LaDuke 1999). Great Britain and the U.S. exploded 1,054 nuclear devices, both above ground and below ground between 1951 and 1992. From 1951 to mid-1962, the NTS was a primary site for both surface and above-ground nuclear testing, with eighty-six tests conducted at or above ground level, and 14 other tests that were underground - making the Shoshone nation the most (nuclear) bombed nation on earth (Churchill, 1997).

The location of the tests was selected specifically because an isolated region was needed with a relatively low population zone, where coincidentally, one of the poorest populations lived. To sustain the nuclear arms race, tests had to be conducted, but the tests could not take place close to larger populations. The tests were specifically done when

the wind was blowing away from Las Vegas (about 70 miles southeast), so the radioactive material would not drift toward the city. Instead, it covered the Shoshone reservation (Clark 2002) and further south.

The nuclear explosions produced a characteristic mushroom cloud, which moved “downwind” as it reached its stabilization height. Dispersion of the radioactive elements caused vertical and lateral cloud movement, spreading radioactive materials over adjacent regions. While the large particles settled nearby the site of the detonation, smaller particles and gases may be dispersed around the world (Clark 2002).

In a report by the National Cancer Institute (1997), it was determined that the nearly ninety atmospheric tests at the NTC left high levels of radioactive iodine-131 across a large area of the continental United States, especially in the years 1952, 1953, 1955 and 1957 (Hundahl, 1998; Simon, Bouville and Land, 2006).

Following decades of denial by the federal government who routinely assured the public that radioactive fallout from nuclear weapons testing was harmless, in 1990 Congress passed the Radiation Exposure Compensation Act (RECA). RECA established lump sum compensation awards for individuals who contracted specified diseases in three defined populations: uranium miners, millers, and ore transporters, who received \$100,000; individuals present at atmospheric nuclear weapons tests, who received \$75,000 (“onsite participants”) and individuals who lived downwind of the NTS, who received \$50,000 (“downwinders”). Surviving

family members of deceased individuals who lived downwind were also eligible to receive compensation. The vast majority of claims have been filed by people living the Four Corners Region (Utah, Colorado, New Mexico and Arizona). The program regularly engages in outreach efforts to the Navajo, Hopi and Yavapai-Apache tribal communities, conducts town hall meetings, and assists members in filing claims (U.S. Department of Justice 2009).

RECA COVERED AREAS

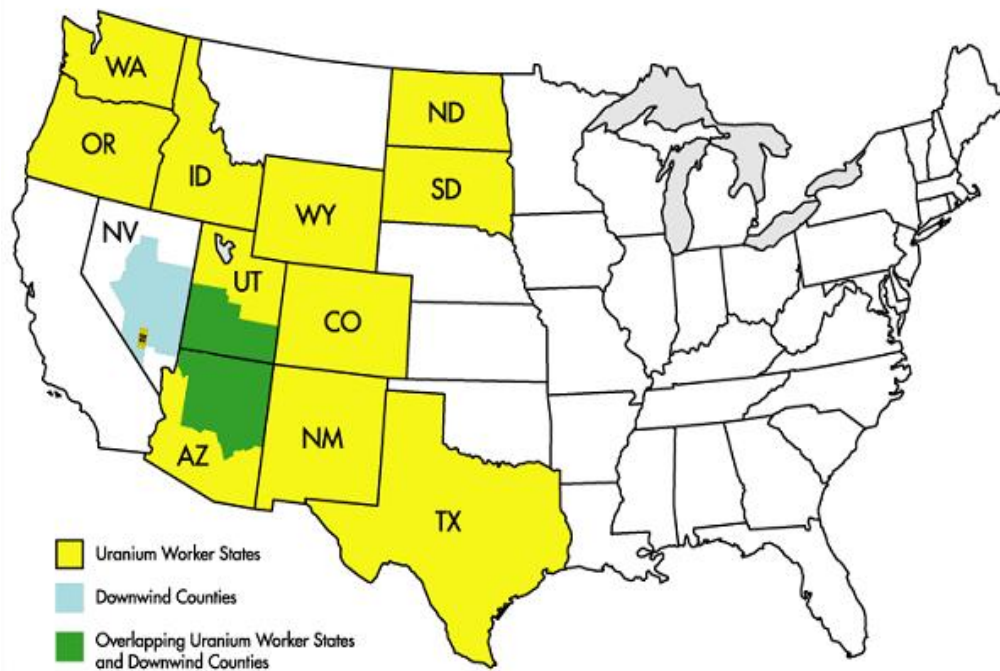


Figure 1. Map of designated geographic areas that qualify for RECA (Source: U.S. Department of Justice)

The specific diseases recognized as resulting from fallout include: leukemia (other than chronic lymphocytic leukemia), lung cancer, multiple myeloma, lymphomas (other than Hodgkin's disease), and primary cancer of the thyroid, male or female breast, esophagus, stomach, pharynx, small intestine, pancreas, bile ducts, gall bladder, salivary gland, urinary bladder, brain, colon, ovary, or liver (Broderson, 2002; U.S. DOJ 2009).

The NCI report (1997) estimates that radiation doses received during these years (1952, 1953, 1955 and 1957) are estimated to be large enough to produce 10,000 to 75,000 additional cases of thyroid cancer in the overall U.S. population. Another report published by the Scientific Research Society, estimates that about 22,000 additional radiation-related cancers and 2,000 additional deaths from radiation-related leukemia are expected to occur in the U.S. because of external and internal radiation from both NTS and global fallout (Simon et al., 2006).

As of February 27, 2011, over 33,353 RECA claims have been submitted, with 72% approved for compensation. Of the total claims, the largest numbers of claims that have been submitted are by "downwinders" at 19,000, with 80% approved or 750 million dollars in awarded compensation. To date, a total of 1.5 billion dollars has been awarded for all approved claims (U.S. DOJ, 2011).

The Role of Tribal Sovereignty

For Native peoples, environmental justice includes a different set of issues than it does for other affected groups. Environmental justice

requires attention to the interrelated cultural, spiritual, social, ecological, economic, and political dimensions of environmental issues. For tribal communities in the United States, environmental justice cannot be discussed apart from recognition of tribes' unique legal and political status – tribes are sovereign governments, with rights to and management authority over tribal lands and resources (O'Neill 2003).

Native tribes were functioning communities with their own powers and forms of government long before European settlers arrived in the new world. The two concepts of power and form of government are important when analyzing Native American tribal jurisdiction, and is especially relevant in the discussion of environmental justice. The federal government's recognition of tribal power is based on the concept of pre-existing Native sovereignty. Tribal sovereignty is not based on any granting or giving of power by Congress to tribal nations; rather sovereignty is something that is retained by tribal nations from their original power. Under federal Indian law, tribal power was recognized through concepts of international law (McNally 1996).

Dean Suagee, a prominent Native attorney who developed the first Indian Country Environmental Justice Clinic, observed that for Indian tribes, "the concept of environmental justice is not very useful unless it is broader than just the intersection of civil rights and environmental law" (Suagee 1998, p. 572). Instead, he states, "in Indian country a vision of environmental justice must also include the tribal right of self-government.

Unless the larger American society honors the tribal right of self-government, the word 'justice' as applied to Indian communities simply does not have much meaning" (Suagee 1998, p. 572).

Tribes have been aggressive in protecting their right to self-governance and self-determination, often in the face of considerable opposition. The assertion of sovereignty has become increasingly evident and critical in the area of environmental management (McNally 1996).

Suagee has stated, ". . .tribal governments must be involved in performing the full range of functions that governments are expected to do in protecting the environment: making the law, implementing the law, and resolving disputes" (Suagee 1998, p. 572). In the context of environmental justice, the injustice faced by federally recognized tribes was primarily caused by the federal government's failure to acknowledge the tribes' sovereign powers and "by decades of paternalistic federal management policies, which had allowed reservation resources to be exploited without adequate compensation or mitigation" (Tsosie 2007, p. 1632).

Tribal amendments were made to many of the major federal environmental statutes enacted in the late 1980s and early 1990s to include express provisions for Indian country, enabling tribal nations to set their own standards for water and air quality and assume regulatory authority over their reservation lands in partnership with the Environmental Protection Agency (EPA) (Tsosie 2007). Given their powers of self-

government, each tribe can develop their own resource management regulations and systems, as long as both comply with federal regulations (McNally 1996).

Today, the active implementation of tribal regulatory over the reservation environment is seen as an answer to the perceived victimization of reservation communities by exploitive and environmentally hazardous industries. Currently the EPA supports an Advisory Council on Environmental Justice, which includes an Indigenous Peoples Subcommittee, charged with ensuring that Native peoples have a role in environmental decision-making (Rogers, 2005).

Increased technical assistance and greater involvement by tribes at the federal level will allow for informed decision-making and opportunity for tribes to resolve environmental issues that impact their communities directly. This type of empowerment through education and knowledge will begin to address the generations of marginalization and discrimination that have characterized mainstream society's relationships with tribes throughout history. The application of a true environmental justice will reflect an approach of tribal self-determination empowered by knowledge.

Applying Community-Based Participatory Research in Addressing Health Disparities among American Indians and Alaska Natives

The principle that underlies problems of ethics is respecting the humanity of others as one would have others respect one's own. But if they do not feel such respect, then no matter how scrupulously they follow the letter of the written codes of

professional ethics, or follow the recommended procedures of field (research) manuals, they will betray themselves all along the line in the little things. (Goodenough 1980, p. 52)

Carson and Hand (1999) claim that “Native Americans have been studied more than any other group ... yet they remain among the most disadvantaged groups within the United States” (p. 161). This statement begs the question: Why hasn't research made a difference for Native American people? Challenges to conducting research with Native American communities include a long-standing, well-founded distrust of research that, at times, has represented yet another means of oppression by the predominant culture. Even the best intentions of scientists may go awry in the interface between the sometimes immensely diverse worldviews of the scientific and the Native American communities. Using a community based participatory research (CBPR) approach to form academic community partnerships with Native American people may provide a means to rebuild trust in the research process while addressing existing health disparities.

There has been a long history of research in American Indian/Alaska Native (AI/AN) communities (Davis and Keemer, 2002), and AI/AN people are one of the most heavily-studied groups in the U.S. A recent search on PubMed, one of the nation's largest search engines for medical science articles dating from the 1950s to the present, yielded over 3,000 articles about AI/AN communities (Sahota, 2009). The reasons for so much research in Indian Country are probably complex, and include (1)

the high prevalence of certain health disparities in AI/AN communities, such as diabetes, heart disease, and alcohol use; (2) recent priorities in federal funding for research with ethnic minority groups; and (3) non-AI/AN researchers' interest in working with AI/AN groups who they view as "romantic" or "exotic" (Brugge and Missaghian, 2006).

A prime example of one of the longest histories of biomedical research conducted in an American Indian community is the Gila River Indian Community. It is considered to be "one of the most scrutinized and surveilled communities in the world, with data flowing from multiple simultaneous research catheters" (Smith-Morris, 2007; p. 328). The Indian Health Service (IHS) deployed some of its first clinicians in the community due to the epidemic of diabetes among the Pimas, followed by the National Institute of Diabetes, Digestive and Kidney Disorders (NIDDKD). Their established presence began over 40 years ago. In discussions that Carolyn Smith-Morris had with community members, Pimas have suggested that the research is "(a) never going to produce a cure or reasonable control mechanisms, (b) a somehow fake or exploitive scheme by outsiders, or (c) targets benefits for non-Pima and non-Indian sufferers, rather than the community-specific needs of the Pima themselves" (2007, p. 331).

Unfortunately, these expressions of mistrust have in some instances proven to be true. Currently, more than 80% of community members develop diabetes by age 55 (Papov, 2007). This is despite over

four decades of research that has been conducted, involving over $\frac{3}{4}$ of the population. Many of the tremendous worldwide advances in Type 1 research and treatment have come as a direct result of these research studies. However, tragically, the members of the GRIC have seen almost none of these benefits because they are affected primarily by Type 2 rather than Type 1 diabetes.

The history of research in Indian Country has also included some instances of direct harm to AI/AN communities. Examples include the hantavirus pulmonary syndrome - originally called Navajo flu (Saltzstein, 1993), and the Barrow Alcohol Study (Manson et al., 2004). The latest publicized example of harmful research is described in the now-infamous lawsuit the Havasupai Tribe filed against Arizona State University (ASU) (Rubin, 2004; Havasupai Tribe vs. Arizona State University). In February 2004, the Tribe filed a \$50 million lawsuit, against the university and its Board of Directors, as well as the three professor/researchers from ASU, charging the misuse of blood samples taken from tribal members (Shaffer, 2004; Harmon, 2010). The Tribe claims that tribal members were told their blood samples would be used for a study on the genetics of diabetes. However, the samples were also used for studies on schizophrenia, inbreeding, and possible migration patterns of the tribe's ancestors from Asia to America. Although it was the anthropologist who "blew the whistle" on the subsequent research when he discovered that blood samples taken for the diabetes study had given to others for other research (Parezo,

2004), the Havasupai sued over a lack of oversight by the university's Institutional Review Board (IRB) in violation of federal law. A number of papers were published in scientific journals discussing these research results, which Havasupai Tribe members say was humiliating and harmful to them (Rubin, 2004). This case was widely publicized and discussed throughout Indian communities, with many tribes and AI/AN organizations, including the National Congress of American Indians (NCAI), passing resolutions (NCAI Resolution, SAC-06-019) expressing support for the Havasupai Tribe's lawsuit against ASU. This case also caused many AI/AN communities to seek new ways to protect themselves from being deceived about the purposes of research projects and to control how their communities are portrayed in publications or presentations by researchers.

These instances have led to a growing mistrust of outside researchers and the institutions they represent. Tribal communities, however, still face the dilemma of effectively addressing the health disparities currently affecting their quality of life. Community-based participatory research (CBPR) approaches seek to reverse this pattern by building trust between community members and researchers.

CBPR is a philosophy, approach and methodology for research. It utilizes a partnership approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process, in which all partners contribute

expertise and share decision making and responsibility (Israel et al, 1998).

The principles of CBPR most often found in the literature were eight initially identified by Israel and colleagues in 1998 (Israel et al., 1998) and include:

- 1) recognition of the community as a unit of identity
- 2) builds on the strengths and resources within community
- 3) facilitates collaborative, equitable partnership in all phases of research
- 4) integrates knowledge and action for mutual benefit of all partners.
- 5) promotes a co-learning and empowering process that attends to social inequalities
- 6) involves a cyclical and iterative process
- 7) addresses health from both positive and ecological perspectives
- 8) disseminate findings and knowledge to all partners and involves them in the dissemination process

The literature contains many recommendations for conducting research with AI/AN populations, including the importance of building trust. There are also examples of intervention research projects that have worked to build trust between American Indian communities and academic researchers and the lessons learned. These include CBPR approaches: between the Crow (Apsaalooke) Indian Nation and Montana State University utilizing lay health advisors to decrease cervical cancer (Christopher, 2005); a NCI Cancer Disparities Research Partnership

between the Rapid City Regional Hospital and members of three Lakota tribes (Oglala, Rosebud, and Cheyenne River Sioux) in western South Dakota to reduce cancer mortality rates in the region (Rogers, 2005); and successful strategies with three tribal communities (Eastern Band Cherokee Indians, the Cherokee Nation of Oklahoma and Lakota tribal members living in Rapid City, SD) and the University of Colorado Health Sciences Center in aging and health research emphasizing access, local relevance and decision-making processes (Manson et al., 2004).

CBPR would seem to be the most appropriate approach to changing the negative history of research encounters in Native American communities into a more productive and beneficial partnership in effectively addressing community health disparities.

Based on the literature, it is clear that there exist major health disparities in American Indian and Alaska Native communities when compared with other populations. The challenge is in identifying the starting point in effectively addressing the reduction or elimination of these inequities.

Dr. Gilbert Fridell, the first Director of the Markey Cancer Center at the University of Kentucky, has spent much of his career focused on the issue of health inequity among the medically underserved. He has stated that, "The issues as well as the solutions come from the community." It has often been the mistake of research to look for solutions outside the

community, as well as leaving the community out of the effort in finding the solution.

This dissertation will examine a research project that uses a community-based participatory research (CBPR) approach when applying a cultural consensus method in identifying the collective knowledge and beliefs about the prevention, cause(s), treatment and survivorship of cancer in a southwest American Indian community.

CHAPTER 3

THE COMMUNITY

I don't know about the white people. I don't know who they are, where they come from. We people don't come from nowhere across the ocean. We are raised right here in this country. We come from Sedona, the middle of the world. This is our home. . . We call Sedona Wipuk, that's a kind of stone. Some of my people, they call themselves Wipukpa. . . My people are from Ahagaskiaywa (Montezuma's Well) or the bottomless lake. At the time people lived down in there, there was no water in the lake. After some time there was a flood. People do something wrong, and the rain comes. There is only two of them that come out from the flood. . . a girl and the woodpecker. When this flood started, the people put this girl in a hollow cottonwood log. They put food in the log with her and put a small hole in it. The woodpecker made the hole in the log so she could breathe. The people told the girl to not eat all the food right away. They told her the flood would raise her up and she would hit the sky. "You will hear the noise when the log hits the sky," they said. "Just lay still, and you will get out in the end." The girl stayed in the log 40 days and 40 nights. The girl stayed in there all the time. When the water was gone, she was in a high place people today call Sedona. The girl came out of the log. Her name was Komwidapakwia which means, 'Old Lady White Stone.' She brought a white stone with her which protected her. She was First Woman, and the Yavapai people all come from her. She came out at Sedona where all Indians come from. It is said that her footprints were left in the wet earth and those foot marks were proof that this story is so (Ruland-Thorne, 1993, p. 1, 2).

Yavapai history. . is a story of persistence, change, and persistence through change (Braatz, 2003, p. 22).

History and Background

The Yavapai and Apache people once lived in a large territory located in what is now north-central Arizona. The Yavapai creation story identifies their close ties to a specific geographic area. They came into the world and became the people of the red rock canyons and mountain

areas of central and western Arizona that includes *Ahagaskiaywa*, known today as Montezuma's Well. The area they occupied, prior to European contact, stretched from the San Francisco Peaks in northern Arizona to the Pinal Mountains in the southeast, and to the southwest to the meeting of the Colorado and Gila Rivers. (Harrington, 1908; Braatz, 2003).

The Yavapai originate from Yuman-speaking peoples. They recognized membership in one of four broader regional divisions or bands, often identified as sub-tribes by anthropologists, but understood as separate groups or peoples: Yavapés, Wipukepas, Tolkepayas, and Kwevkepayas (Iverson, 1982). The geographic areas each group identified with were: the Tolkepayas were from western Yavapai territory and the Haassayampa river region; the Kwevkepaya were from the southeastern Yavapai territory; the Yavapé were from the Williamson Valley south across the Bradshaw Mountains and the Agua Fria River; and the Wipukepa were from the Oak Creek Canyon area (Braatz, 2003).

These sub-tribes of Yavapais were also culturally and linguistically related to the upland Pai people to the northwest, which include the Walapais and Havasupais. They shared similar hunting and gathering lifestyles, as well as overlapping geographic range. However, they considered each other outsiders, and often enemies (Iverson, 1982; Braatz, 2002).

The Yavapai could also be linked linguistically to the Mohaves and Yumas, however, they differed in their cultural lifestyle, along with the

Pimas, Maricopas, and Quechans who were sedentary farmers living along rivers in southern and western Arizona. They also differed from the Athapaskan-speaking Western Apache to the east. However, they had some association with both the Tonto and San Carlos Apache, which may have caused confusion in their incorrect identification as Mohave-Apache (Iverson, 1982; Rockwell, 2001; Braatz, 2002).

Yavapais lived in small, independent and highly mobile camps consisting of a single nuclear or extended family that maintained an annual cycle of hunting and gathering, often supplemented by small scale agriculture (Braatz, 1997). Families relocated frequently as they followed the harvesting sequence of wild plant foods, including: agave or mescal, squawberries, assorted greens, mesquite beans, ironwood and palo verde seedpods, walnuts and Manzanita berries, acorns, juniper berries, prickly pear fruits, piñon nuts and assorted berries. The men hunted in all seasons, as wild game was a primary source of protein and included mule deer, pronghorn antelope, elk, and desert bighorn sheep (Braatz, 1997; 2002).

The Kwevkepaya and Wipukepa groups developed historically close alliances with two of the four Western Apache peoples, the Tonto Apaches (or Dilzhe'e) and San Carlos Apaches. Kwevkepayas shared hunting and gathering grounds and intermarried with both Apache groups. The Wipukepas and Tonto Apaches had even closer bonds through sharing of resources along the Upper Verde Valley and Oak Creek

Canyon, as well as through frequent intermarriage and the creation of mixed Yavapai-Apache camps (Braatz, 2002).

Prior to 1860, very few non-Indians entered Yavapai territory. However, their homeland was soon invaded by large numbers of whites in search of gold and farmland. In 1863, gold was discovered in Prescott, located in the middle of the homeland of the Yavapai. The discovery was the beginning of the end of traditional Yavapai culture in the region. American soldiers and settlers disrupted the Yavapai way of life and military campaigns threatened to eliminate their families and communities. From 1863 through 1873, the Yavapai were subjected to constant and brutal wars of conquest conducted by the American government across the Dilzhe'e and Yavapai homelands (Braatz, 1997; Coder, 2005). Yavapai groups responded by either complying with white demands, while others were staunchly resistant. In 1871, President Grant issued an Executive Order establishing a Military Reserve of 900 square miles for the Apaches who came in east of the Verde River and any other tribal people who surrendered locally. In 1873, the Yavapai who were confined at Camp Date Creek were transferred onto the Reserve. However, the Rio Verde Indian Reserve was rescinded by Presidential Order in 1875 and all of the people, both Yavapai and Apache, numbering around 1,700, were forcibly marched 180 miles to the San Carlos (Braatz, 2003) agency east of Phoenix. The forced removal of the indigenous people of the Verde Valley resulted in several hundred lives lost and the loss of several

thousand acres of treaty lands promised to the Yavapai-Apache by the United States Government. The Yavapai and Dilzhe'e Apache remained in internment at San Carlos for 25 years. By the late 1890's the reservation system was breaking down and beginning in 1900 the survivors of the removal began drifting back to their home country in small family groups. When finally released, only 200 actually made it back to their homeland in the Verde Valley. What they found when they returned was that their land had been taken over by Anglo settlers and that there was no longer a place reserved for the Yavapai-Apache people in their own homeland. In 1910 the federal government established the 40-acre Camp Verde Indian Reservation (Gifford, 1933; Iverson, 1982; Rockwell, 2001; Burns, 2002; Braatz, 1997, 2002; Coder, 2005).

There are two additional groups of Yavapai with established reservation communities – the Ft. McDowell Yavapai Nation and the Yavapai Prescott Indian Tribe. Another reservation for the Yavapai and Apache people was created by Executive Order on September 15, 1903. The Kwevkepayas, or Southeastern Yavapai, who lived in the Matagal-Four Peaks and Superstition Mountain region, were granted 24,680 acres of the old Fort McDowell Military Reserve. This was considered one of the most important outposts in the southwest during the Apache Wars which occurred from 1865-1891. The 40-square mile reservation is now home to 600 community members, while another 300 live off reservation. The reservation is a small parcel of land that formerly was the ancestral

territory of the once nomadic Yavapai people, who hunted and gathered food in a vast area of Arizona's desert lowlands and mountainous Mogollon Rim country. The Fort McDowell Yavapai Nation lives on the reservation which lies approximately 23 miles northeast of Phoenix in Maricopa County. The community's economy is closely tied to the surrounding communities of Rio Verde, Fountain Hills, Mesa, Scottsdale and Phoenix (Iverson, 1982; Waterstrat, 1998; Rockwell, 2001; Burns, 2002).

A third Yavapai reservation was established in 1935. The Yavapai Prescott Indian Reservation occupied only 75 acres of the former Fort Whipple Military Reserve in central Arizona. This was the first reservation established solely for the Yavapai. It continued to grow with the 1956 addition of 1,320 acres. Today, the Yavapai Prescott Indian Tribe consists of 159 members and occupies a reservation of less than 1,500 acres (Rockwell, 2001; Braatz, 2003).

Under the Indian Reorganization Act of 1932, the Yavapai and Apache people were officially recognized as sovereign people by the federal government. In 1992, under a revised tribal constitution, the tribe became known as the Yavapai-Apache Nation. Today, the reservation spans over five tribal communities including Camp Verde, Clarkdale, Middle Verde, Rimrock and Tunlii, and encompasses more than 1,600 acres throughout the Verde Valley. The descendants of the Yavapai and Apache people live in each of these communities located in the Upper

Verde Valley of central Arizona off of I-17, 90 miles north of Phoenix and 50 miles south of Flagstaff. Current tribal enrollment of the Yavapai-Apache Nation is 2,289.

In 1993, the Yavapai-Apache Tribal Council approved plans to open a tribal gaming facility. Cliff Castle Casino opened in May 1995. The revenue from the casino and renovated hotel operations has allowed the Yavapai-Apache Nation to build a new health center and a cultural resource center for Tribal members. It houses the offices of the Yavapai and Apache Cultural Preservation Department as well as language programs and the tribal collections. Ninety percent of the tribe's operating costs are designated to provide basic health and social services, law enforcement and a full-time government for its people, most of this comes from gaming revenue. Funding has also allowed the Yavapai-Apache Nation to renovate 80 percent of homes on the reservation. It is the largest employer in the Verde Valley and has contributed to decreasing reservation unemployment to 5 percent. The Nation also provides funding for college scholarships for all tribal members, as well as child and elder care (Piner, 2004).

To be enrolled with the Yavapai-Apache Nation, an individual must be at least $\frac{1}{4}$ Yavapai-Apache or have at least $\frac{1}{4}$ Indian blood with one parent who is an enrolled member. Of the 2,289 total enrolled members, there are 1,083 who live in the Verde Valley. Due to limited land space

and available housing, 969 live within tribal communities. Forty percent of the Nation's population is under the age of 18 years of age.

Challenges to Community Health

Historical Challenges

The medical history of American Indians since contact with Europeans has been characterized as an unnatural history of disease, unnatural because the epidemiology of American Indians and Alaska Natives changed under the hegemony of European contact (Campbell, 1989). There is no argument that tribes suffered incredible loss when they came into contact with white settlers. Premeditated massacres accounted for only a very small proportion of overall Indian deaths. The vast majority of deaths actually resulted from European and African disease that spread through what has been described as "a biological island of human beings who had lived for millennia in isolation from Old World infections" (Bordewich & Scholder, 1996, p. 53). What essentially occurred then, within tribal communities and bands, especially those that were small and isolated, was by any reasonable definition - catastrophic.

The consequences for the Yavapai and Apache were sadly, no exception. European contact brought smallpox, measles, typhus and other diseases that had previously been unknown in the southwest and spread quickly. It has been suggested that smallpox may have first reached the Pueblos of New Mexico in 1625, brought from the south on a mission caravan. From the eastern Pueblos smallpox and other diseases

could have moved on to the Zuni and Hopi villages and their trading partners. Some populations declined by 30 to more than 50 percent before regular missionary contact, and could have potentially reached all Native groups in Arizona by 1660 (Braatz, 2002).

According to Yavapai oral tradition, smallpox first occurred when Yavapai raiders encountered Pima villages south of the Gila River that were suffering from an epidemic. The disease spread north to Yavapai camps and eventually into Pai territory (Gifford, 1933; Reff, 1991; Braatz, 1997). Although it has been suggested that the spread of smallpox caused a decrease in the total Yavapai population, the impact was not as devastating as in some neighboring groups. This may have been due to the small, scattered and regularly relocated settlements. Additionally, initially there was limited contact with European outsiders when compared with other tribal groups with sustained Jesuit contact (Reff, 1991).

During the reservation period, however, the challenge for the Yavapai and Tonto Apache was surviving from disease while in confined living spaces with higher concentrated populations. Dr. William Corbusier, an army surgeon assigned to the Rio Verde Reservation, gave details in his memoir that when he arrived in 1873 he learned:

there was an epidemic resembling the epizootic and much other sickness among the Indians. . . the Indians were in their oowas, or brush and grass shelters. . some of them had chills and fever. . the Indians were along the river lower down and were in a miserable physical condition.. many were half starved and became subject to dysentery and Malaria. Deaths were so frequent that the bodies were left in their oowas to mummify in the dry air or the oowas

burned over them, as there were not enough well Indians to cut and carry the wood with which to burn the dead, as was their custom (Corbusier and Wooster, 2003, p.73, 74).

As illness spread on the reservation, the people turned to the *basemachas*, or healers. Yavapais believed that evil spirits were responsible for disease and injury. Basemachas danced, sang, rattled gourds and smoked different plants to counteract the evil spirits (Braatz, 2002, p. 148). Dr. Corbusier also noted that, “The kith-e-ays, who give medicines and also sing, were all trying to aid the sick” (Corbusier and Wooster, 2003, p. 74). In addition to traditional healing practices, the Yavapais at Rio Verde also adopted the medical practices introduced by Dr. Corbusier by utilizing quinine to help the sick (Corbusier and Wooster, 2003).

In the early twentieth century, the Yavapai and Apache continued to use the medicine of American doctors when it was available, but also continued utilizing traditional healing practices of *basemachas* (Gifford, 1933; Braatz, 2003).

Current Challenges

Some of the current challenges that affect the health and well-being of the Yavapai-Apache community are related to environmental and cultural lifestyle changes that have contributed to a higher risk to potential disease and related illnesses.

Diabetes

American Indians and Alaska Natives carry the heaviest burden of diabetes in the United States, suffering from one of the highest rates of diabetes in the world. In some American Indian and Alaska Native communities, diabetes prevalence among adults is as high as 60%. One out of six American Indian and Alaska Native adults (16.3%) has been diagnosed diabetes—more than double the prevalence rate for the general United States population (IHS, 2000; Acton, 2003).

Once exclusively a disease of adults, type 2 diabetes is increasingly common among American Indian and Alaska Native youth, threatening the health, well-being, and quality of life of future generations.

The interaction among hereditary, behavioral, and environmental factors has left American Indians and Alaska Natives particularly vulnerable to diabetes. These factors include a hereditary predisposition to diabetes, increasingly sedentary lifestyles, exposure to diabetes while in the womb, and the effects of living in adverse social and physical environments, such as living in extreme poverty and rural settings with limited access to fresh fruits and vegetables (IHS, 2000; Acton, 2003).

Nevada nuclear weapons testing and “downwinders”

The 50th anniversary of nuclear weapons testing at the Nevada Test Site occurred in 2001. Many people still suffer from cancer and other diseases caused by fallout from the United States atomic testing program half a century later. The areas in Arizona recognized by the government

as affected by fallout are Yavapai, Coconino, Apache, Gila, and Navajo counties. One out of every seven tests dumped radioactive fallout on northern Arizona (Brodersen, 2003; RECA, 2009).

In spite of decades of denials by government officials who routinely assured the public that radioactive fallout from nuclear weapons testing was harmless, in 1990 Congress passed the Radiation Exposure Compensation Act (RECA). RECA provides \$50,000 per person compensation payments to "Downwinders" who later suffered from specific radiation related cancers and other diseases. The term "Downwinder" refers to anyone who was living in one of the areas contaminated by fallout from the Nevada Test Site during the period of atmospheric (above ground) nuclear testing.

People living or working "downwind" of Nevada Test Site - in northern Arizona, southern Utah, and most of Nevada - for at least two years between January 21, 1951, and October 31, 1958, or in the month of July, 1962 may have suffered cancer and other diseases caused by exposure to radiation.

The specific diseases recognized as resulting from fallout include: leukemia (other than chronic lymphocytic leukemia), lung cancer, multiple myeloma, lymphomas (other than Hodgkin's disease), and primary cancer of the thyroid, male or female breast, esophagus, stomach, pharynx, small intestine, pancreas, bile ducts, gall bladder, salivary gland, urinary bladder, brain, colon, ovary, or liver (Brodersen, 2003; RECA, 2009).

Although the vast majority of claims are filed by people living in the Four Corners Region (Utah, Colorado, New Mexico, and Arizona), the Program has awarded compensation to individuals residing in every state as well as several foreign countries. The claimant population has also included several Native American tribes. The RECA Program engages in outreach to the Navajo, Hopi, and Yavapai Apache Indian reservations to meet with tribal leaders, conduct town hall meetings, and assist members in filing claims.

Several families within the Yavapai-Apache community have been affected as “downwinders” and received compensation due to multiple cases of cancer that have been identified.

Environmental pollutants

There has been cause for concern over the past decade related to the environmental pollutants due to the history of the mining industry in the Verde Valley and the potential relationship to higher cancer rates.

The Verde Valley is the home of one of Arizona’s largest copper mines, the Phelps-Dodge mine at Clarkdale. Copper mining began in 1865 and continued until 1948. When operations ended, the smelter was closed and the site abandoned (Foust, 2004).

Of the 15 counties in Arizona, Yavapai County ranks in the top five for not only breast cancer, but lung and bladder cancers as well (Beyer, 2009). It also has the worst rate in the state for prostate cancer, according to the Arizona Department of Health Services (ADHS 2005).

Arsenic levels were reported to exceed federal limits in 20 of the 21 wells in the Cottonwood Municipal Water System. Warning letters were sent out to residents in 2009 stating, “You may have an increased risk of getting cancer.”

An unusually large number of livestock delivered stillborn babies during a recent drought period at a Verde Valley ranch located approximately 35 km downstream from the Clarkdale mine tailings. Several chickens on the same farm died in the following weeks. Arsenic poisoning was suspected as the probable cause (WHO, 2001; Foust, 2004).

The source of the Verde Valley’s high levels of arsenic has been traced to the area’s mining history. Residents in the community say the tailing and slag piles left over from the mining business are hard to ignore. When the Environmental Protection Agency (EPA) and the Arizona Department of Environmental Quality were contacted in 2009 by a resident group, they indicated that the tailings were too toxic to move. They were also told that the arsenic and lead came from mining company Phelps Dodge, and the company had violated EPA standards for water contamination. Phelps Dodge eventually constructed an EPA mandated barrier to stop contamination (Scorecard, 2004; Foust, 2004).

Addressing Health and Wellness

In a report completed by the public health nursing program of the Phoenix Indian Medical Center (Hall, 2001), community health workers, as

well as community residents were surveyed in identifying the top five causes of morbidity among Yavapai-Apache tribal residents. They were identified as: diabetes and related complications, hypertension, alcohol and substance abuse, teenage pregnancy and accidents/injuries.

For the year 2000, 625 enrolled Yavapai-Apaches were active users of services provided at the Phoenix Indian Medical Center (PIMC), resulting in 35 admissions and 1174 ambulatory visits. The majority of visits were designated as “subspecialty care” (e.g., diabetes, oncology) according to data provided from the tribe’s health and human services department.

The Arizona Department of Health Services (ADHS) indicates that for all residents of Arizona, the average age at death is 71.7 years. However, the average age of death for Arizona’s Native populations is 55.7 years. Mortality statistics provided by the Yavapai-Apache Nations’ enrollment office indicate that for the year 2000, the age of death ranged from 38 to 61 years of age with the average age of death as 51.7 years of age.

In the past, the Yavapai-Apache Nation has had several ad hoc “health committees” that have attempted to work with the Indian Health Service (IHS) and/or set priorities for the tribe’s health and social service programs related to improving the health status of the community. In 2001, the tribe completed and opened a new 5,500 square foot ambulatory clinic. The facility has two exam rooms, dental and optometry

suites, and offices for the Community Health Representative (CHR) and Alcohol/Substance Abuse Prevention staff. The tribe contracted with a health planner/consultant to develop an operational plan for the provision of health care services in the new medical facility. Currently, the tribe is taking steps to implement the plan of a fully operational health department with provision of prevention education and primary health care services.

Primary and secondary prevention services are provided directly on-site from the Phoenix Indian Medical Center (PIMC), Indian Health Service (IHS) and include primary care, dental services, optometry, audiology, behavioral health, social services, health education, and nutrition services. Public Health Nursing (PHN) is provided through a grant, and the Western Arizona District Office provides environmental health services. Approximately 80 – 85% of the PHN's time is spent with the Yavapai-Apache Nation. Pharmacy services are provided through contract health services (CHS) by the local pharmacy in Cottonwood. Laboratory services are provided by the Phoenix Indian Medical Center (PIMC), and radiology services are provided locally at the Verde Valley Medical Center, again through CHS. Tribal employees are covered by private health insurance, while a large percentage of other members may qualify for the state AHCCCS (Medicaid program). Specialty care services are provided locally and at PIMC depending on the patient's circumstances.

Tribally administered health programs include: the Community Health Representative (CHR) Program, public health nursing (PHN), social services, alcohol and substance abuse program, a homemaker program, a diabetes program, Women Infant and Children's (WIC) program, a Wellness program, a food bank, a Senior program (provides daily meals and activities) and a recreation program (provides youth/adult activities and after school and extra-curricular activities for tribal youth).

In-patient services are available from three non-tribal sources: the Verde Valley Medical Center (30 minutes); Prescott Regional Hospital (45 miles); the Flagstaff Regional Medical Center (55 miles north); and the Phoenix Indian Medical Center (PIMC), an Indian Health Service facility (100 miles south).

The Yavapai-Apache Nation submitted a proposal and was awarded funding from the Susan G. Komen Foundation for a Breast Cancer Awareness Project in 2004. The goal of the project was to promote wellness among the women of the Yavapai-Apache Nation by developing and enhancing access to resources for education, screening, and treatment support for breast cancer.

Information provided from a verbal report provided by the Community Health Representative (CHR) program has indicated that there are approximately ten (10) breast cancer survivors in the community. This would indicate that the breast cancer incidence rates reflect the national rates in AI/AN communities of lower rates than the general

population. Additionally, the current cancer mortality rate is also consistent with the higher rates mortality due to late stage diagnosis that is reflective of the experience of cancer health disparities within AI/AN communities. Currently, the Arizona Department of Health Services indicates that compared to Arizona's average age-adjusted cancer mortality rate from 1999-2001 (173.7/100,000), Yavapai County (where the Yavapai-Apache Nation is located) has the second highest death rate due to cancer (196.4/100,00) in the state (ADHS, 2005).

Information provided by the Tribal Health Department staff indicates that the experience of cancer in the community is consistent with late diagnosis. As a result, it has had a tremendous impact on the experience and involvement of extended families, as well as the entire community.

The experience of the community is similar to the findings indicated in a recently completed study reviewing breast cancer incidence data among AI/AN from the NPCR and the SEER combined to estimate age-adjusted rates for the diagnosis years 1999 through 2004. It has provided the most comprehensive breast cancer incidence data for AI/AN women to date and has confirmed that nationally a large percentage of AI/AN women are diagnosed with advanced or late stage breast cancer (Wingo, King, Swan et al., 2008). The staging of cancer can be a useful marker to indicate inadequate screening mammography services at the population level. Previous studies have also identified several factors associated with the late stage at breast cancer diagnosis, including failure to adhere to

screening guidelines, age, less education, race, and factors associated with decreased access to care (e.g., lower income, residence in socioeconomically distressed counties, higher population density, rural residence, residence in medically underserved urban areas, and lack of healthcare insurance or underinsurance) (Braun, Look, & Sark, 1995; Department of Health and Human Services, 2000; Horner, 1990).

The nature of a late stage diagnosis is such that the sequence from initial diagnosis to death is vastly accelerated with the consequences primarily of crisis management and shock and the resulting death of the community member. As a result, there is much fear associated with discussion about cancer and its diagnosis. The CHR has indicated that several community members with a cancer diagnosis do not wish to be identified and are hesitant to participate in any support group programs. Families of the patients, however, consistently request additional information and assistance in understanding what is happening to the diagnosed family member.

The Future

The Yavapai and Apache community of the Verde Valley continue to grow and thrive as a people. As an Indian tribe, they have had to overcome many challenges including invasion by outsiders, the brutal military conquest by the United States government, incarceration, and banishment and relinquishing of their homeland. They have survived historical epidemics of newly introduced diseases, as well as the

environmental and cultural lifestyle impacts that have impacted their current health status. But they have continued to maintain their sovereignty, cohesiveness and resilience as a community and to preserve their language, culture and history. They have successfully exercised their self-determination as a tribal community in securing their future economic security, cultural preservation and health and well-being.



Figure 2 - The Yavapai-Apache Tribal Administration Complex, Middle Verde (Source: C.Claus)



Figure 3 - *Ahagaskiywa*, known today as Montezuma's Well
(Source: Yavapai Apache Nation)

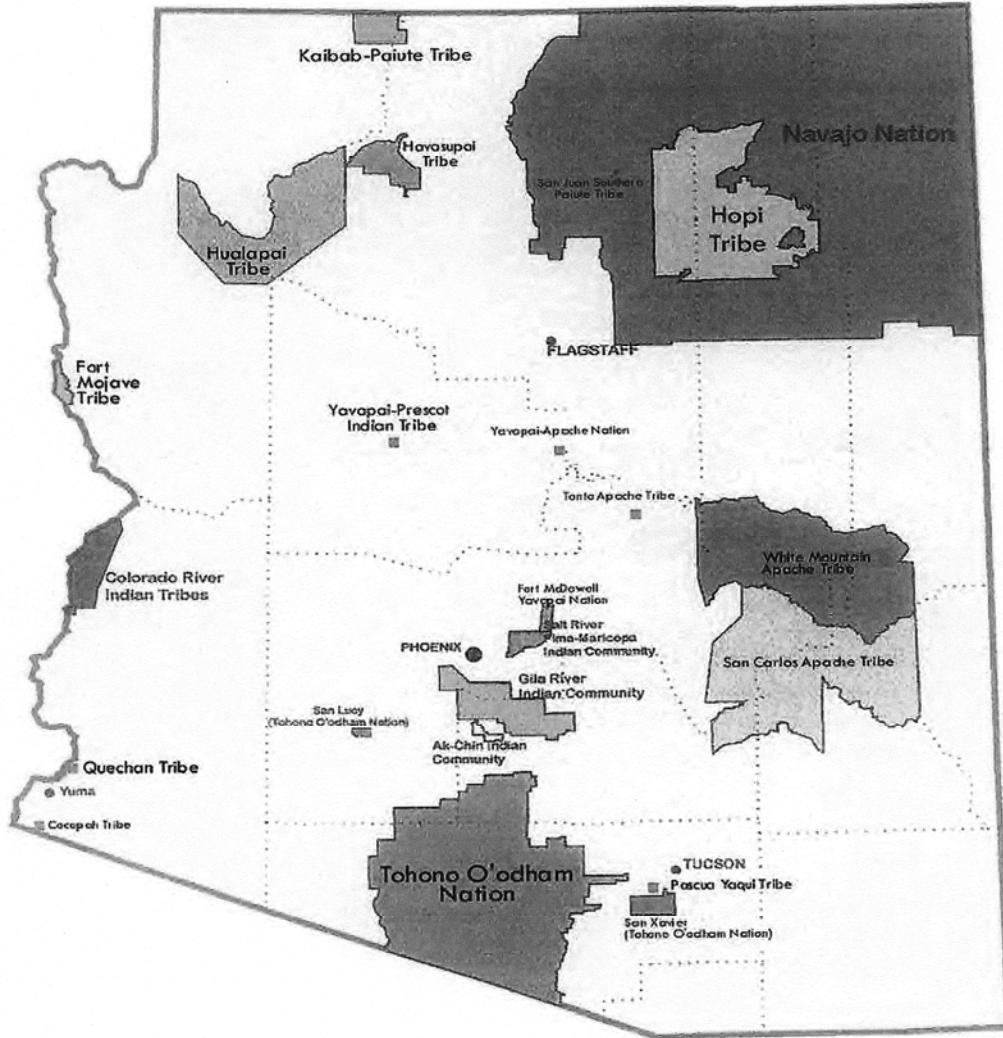


Figure 4 - Map of locations of Arizona Tribal communities



Figure 5 - Yavapai-Apache mother with child
(Source: Yavapai-Apache Nation)



Figure 6 - Annual Re-enactment of the Tribal Exodus
(Source: Yavapai-Apache Nation)



Figure 7 - Sunrise Ceremony (Source: Yavapai-Apache Nation)

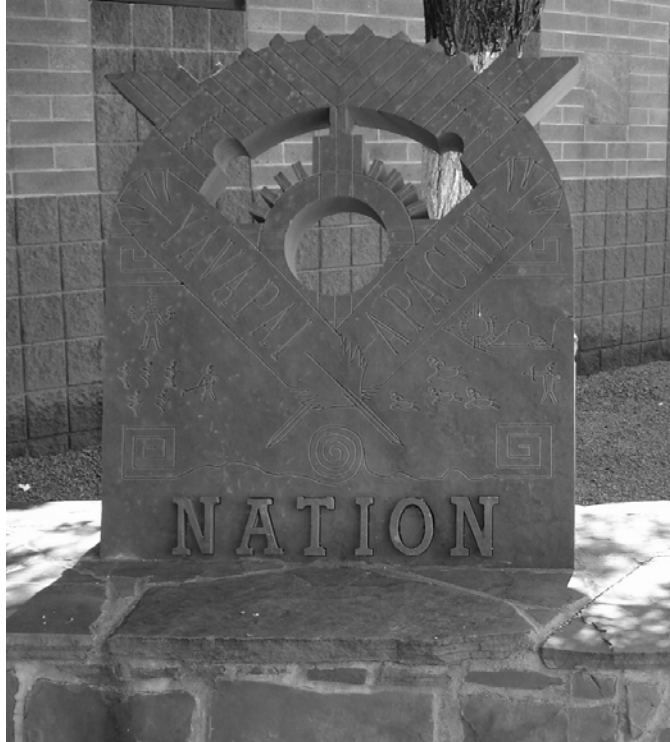


Figure 8 - Yavapai-Apache Tribal Seal (Source: C. Claus)



Figure 9 - Yavapai-Apache Health Center (Source: C. Claus)

CHAPTER 4

METHODOLOGY: THEORIES AND METHODS

The Analysis of Culture

Cultural Models

During the 1970's, Byron Good, Arthur Kleinman and others wrote a series of articles exploring a meaning-centered approach in medical anthropology. Their focus was the way in which groups and individuals constructed explanations of their own suffering and the way in which those constructions were an expression of their social suffering (Dressler, 2001). Medical anthropologist Byron Good and medical sociologist Mary-Jo DelVecchio Good developed a definition and description that captured the basic assumptions of the interpretive perspective:

An illness or a symptom condenses a network of meanings for the sufferer: personal trauma, life stresses, fears and expectations about the illness, social reaction of friends and authorities, and therapeutic experiences. The meaning of illness for an individual is grounded in – though not reducible to – the network of meanings an illness has in a particular culture: the metaphors associated with a disease, the ethnomedical theories, the basic values and conceptual forms, and the care patterns that shape the experience of the illness and the social reactions to the sufferer in a given society. (Good & Good, 1980, p. 166).

A number of issues of wider concern have challenged a meaning centered approach to understanding disease. The first has been an overemphasis on the role of culture – the cultural explanation - for understanding politically sensitive issues especially in relationship to the utilization of medical services. During the 1950s and 1960s, cultural

beliefs (such as fatalism, lack of future orientation, ingrained cultural values) were used in a simple and naïve way to explain behavior, an approach that was criticized, as “blaming the victims” for their disadvantaged social status (Chavez, McMullin, Mishra, & Hubbell, 2001; Rosaldo 1993). Since the 1960s, the pendulum shifted to more structural explanations for the lack of use of medical services, such as the availability of services, poverty, medical insurance, work contingencies, lack of child care, and other factors associated with the political economy of health care. Language and other communication-related barriers were also included in this structural framework (Chavez et al., 2001).

Second, scholars with a positivist viewpoint have criticized the cultural meaning model as insufficiently scientific. The primary criticism concerns the lack of objectivity in measuring the value of cultural influence and beliefs (Leslie, 2001).

What is needed, then, is to apply a model or theory that attempts to make objective the criteria by which we measure our confidence in inferring answers to cultural questions, to help answer the epistemological question of “how do we know when we know?” (Romney, Weller, & Batchelder, 1986, p 163). Utilizing a meaning centered approach coupled with the analytic power of a cultural consensus model, will enable anthropological researchers to go beyond a purely qualitative conception of collective meaning and move to operationalize these constructs through quantitative measurement (Dressler, 2005).

The first step to operationalizing culture is to define what culture is and what the appropriate units of cultural analysis are. Definitions of culture and its analytical components have been wide-ranging in anthropology. Many definitions have polarized towards 1) a Geertzian approach, in which culture is thought to exist only in its public practice and social exchange, or 2) a cognitive approach, in which culture is thought to exist in individual mental constructions (Shore 1996). Another approach advocated by Shore, D'Andrade and others, views culture as a system of models, or schemas. This approach combines elements of mental and practice-oriented views of culture, since cultural model can "exist both as public artifacts 'in the world' and as cognitive constructs 'in the mind' of members of a community" (Shore 1996). In particular, this approach defines culture by the relationship between these public and individual components – as cognitive models that are shared by the members of a community or cultural group (D'Andrade 1995; 2001). In other words, while individuals have personal mental models that are part of their own idiosyncratic way of seeing the world, they also have cognitive models that are shared with other members of their community. It is only those cognitive models that are shared among the members of a community that are truly cultural, and therefore represent and reflect public practice as social interaction.

Cultural Consensus Theory

The notion of sharing culture or consensus is vital in the theory of culture, and has been recognized for well over a century in the social sciences. D'Andrade states that “many (although probably not all) cultural models define things in the world in an essentially arbitrary way. What gives these arbitrary definitions causal force in the world is that people agree that this is, indeed, the way things are” (D'Andrade, 1984). In other words, culture is considered to consist of shared knowledge and meaning – a cognitive anthropological perspective. This perspective is grounded in the idea that it is not enough to simply identify particular characteristics, ideas, or behaviors shared among individuals in a group, but that it is the meaning of these concepts that really matters.

Understanding the importance of consensus is crucial; defining consensus empirically is another matter. Most theories that give prominence to consensus in cultural models seem to imply that consensus is a dichotomy, which Dressler states must certainly not be the case. People may agree on the nature of cultural things to a degree, leaving room for some models to be highly contested, whereas others are accepted with little dispute (Dressler, 2005). Romney et al. (1986) introduced the cultural consensus model that accomplishes the task of quantifying consensus in 1986. Working from the pattern of agreement among key informants, the cultural consensus model determines precisely the degree of sharing in a domain. “The degree of consensus in a domain

enables the analyst to infer within certain confidence limits that these informants are, or are not, operating from a shared cultural model” (Romney, Weller, & Batchelder, 1986, p. 316). Additionally, the cultural consensus model can operationalize the concept of cultural competence (first introduced by Keesing) as the correlation between an individual’s understanding of the domain and the consensus understanding of the domain (Dressler, 2005).

A semantic or cultural domain is basically any subject matter that can be coherently defined (Weller and Romney 1988). According to Weller and Romney a domain is “an organized set of words, concepts, or sentences, all on the same level of contrast, that jointly refer to a single conceptual sphere” (1988, p. 9). Cultural domains can be organized around almost anything; they can be kinship term, animal categories, and beliefs about symptoms of disease and so on. Among other things, understanding a domain helps us understand how the world around us works and how to function in it (Dressler and Bindon 2000).

An individual’s knowledge of a domain is determined by measuring competency, or the degree of agreement with others. Competence is a percentage score indicating the degree of correspondence between an individual and the aggregate response of the group. People with higher competence have a higher correlation of answers among themselves than with less competent people because they share specialized information. If there is an overall agreement among group members about the domain,

a consensus does exist. Consensus infers that information has been shared, creating a coherent system of information for the domain (Romney, Weller and Batchelder 1986).

The cultural consensus model enables the analyst to estimate the culturally best set of responses within a particular domain. The responses are estimated by giving higher weight to the informants who have higher cultural competence (or, in other words, who can replicate more closely the group-level responses). In utilizing the model, Dressler states that this latter characteristic of the model is particularly important, “not only because it allows these responses to be estimated in the most culturally unbiased way, but also because with those estimates that elusive aggregate quality of culture can sensibly be grasped” (Dressler, 2005, p. 26). The culturally unbiased responses estimated from the model are not a simple average, but rather take into account the way in which meaning is distributed among the informants. “It is a function not of what any individual knows, but rather of how that knowledge is distributed” (Dressler, 2005, p. 26).

The primary application of the cultural consensus model, as developed by Romney and Weller et al, is that it provides a method to measure the shared knowledge present in a group of people under the assumption that there is a single shared cultural basis for their knowledge – the assumed answer key. If no single source of shared cultural knowledge is present, the method will not be able to detect any. Thus the

method cannot tell us anything about knowledge to be invented or developed in the future (Romney, Weller, & Batchelder, 1988).

Cultural Consensus Analysis Methods

Cultural consensus analysis (CCA), as developed by Romney et al, is a systematic ethnographic technique of analyzing culture. It asks three primary questions: 1) Does a group of individuals share knowledge in a specifically defined domain? 2) What is the content of that knowledge (“culturally correct” answers to questions)? and 3) What is the relationship of individual informant command of cultural knowledge (“cultural competence”)? Using a cognitive model of culture (such as that outlined by D’Andrade 1984), it may be argued that any cultural knowledge must be shared within a social group. In consensus analysis, the first step is to determine whether the level of agreement within a set of informants is sufficient to assume that they share the same basic knowledge of some domain; shared knowledge is assumed to be derived from a shared cultural model of that domain. If this assumption is supported, than a composite estimate of that shared knowledge can be generated (Dressler, Balieiro, & Dos Santos, 1998).

Three primary consensus analysis methods were developed around the type of data (level of measurement) that each method handles. The original consensus analysis method – the cultural consensus model (Romney, Weller, and Batchelder 1986) was developed to perform consensus analysis on nominal data. This original cultural consensus

model was subsequently altered to accommodate ordinal (Romney, Batchelder, and Weller 1987) and interval (Weller 2007) data.

Subsequent research has extended these techniques to provide a more comprehensive view of a cultural domain. For example, if the consensus analysis suggests that a group of people do share a set of beliefs, then the intracultural heterogeneity of the group can be examined empirically. In addition, Handwerker (2002) has forwarded a method that uses consensus theory to examine intercultural variation. Finally Dressler et al. (2005) have coined the term “cultural consonance (p. 331),” or the extent to which a person approximates in their own belief or behavior the cultural model that a group shares. Dressler et al. (2005) measure cultural consonance using the estimates provided by consensus analysis.

Cultural consensus analysis is a factor analytic-type technique that examines the extent to which individuals agree with one another in a set of data (Handwerker et al., 1997). Cultural consensus analysis produces three sets of parameters. First, it produces an eigenvalue ratio that indicates whether there is a sufficient level of agreement among individuals in the analysis to conclude that a shared cultural model exists. If the first eigenvalue is at least three times that of the second, a shared model can be inferred (Romney et al., 1986). Second, cultural consensus analysis reveals the extent to which each individual agrees with the group’s model, referred to as his or her “cultural competence.” A high level of competence is signified by a competence coefficient of at least

.50. The third key piece of information given by cultural consensus analysis is the cultural best, or “correct” answers for the domain also referred to as the cultural answer key. Culturally correct answers are calculated by weighting the answers of those individuals whose knowledge of the domain most closely resembles that of the group-referred to as the most “competent” participants in the sample-more heavily.

The consensus model, as demonstrated in recent research (Chavez, McMullin, Mishra, & Hubbell, 2001; Dressler, Balieiro, & Dos Santos, 1998; Weller, Pachter, Trotter, & Baer, 1993), provides an operational specificity that has been missing in traditional ethnographic research.

Critiques

There have been several criticisms with regard to the use of cultural consensus analysis. In *Interpretation of Cultures* (1973), Geertz criticizes Goodenough’s view of culture which Geertz labels “ethnoscience” (p. 11), or cognitive anthropology. While cognitive anthropologists view cultural meaning as existing in the minds of individuals, Geertz views meaning as public, or existing in an external sense (White 1959). Geertz also accuses cognitive anthropology of reifying and reducing culture. The reification of culture is said to occur when culture is categorized into something (D’Andrade 1999) that it is not and given culture forces of its own (Geertz 1973). Finally, Geertz also claims that by limiting culture to shared cultural

knowledge, culture is reduced to only a fraction of its true essence. For example, Hannerz (1992) defines three dimensions of culture. While one of Hannerz's three dimensions closely resembles shared knowledge, another, "forms of externalization" (p. 7) is something much less related to shared knowledge.

A second criticism of consensus analysis has been for the potentially over-limiting assumption of a single unified culture. Handwerker (2002), and Caulkins and Hyatt (1999) have argued that culture, particularly in contemporary global contexts, is fluid, contested, and multidimensional. They suggest that important cultural diversity around a domain can exist within a community or culture group, and that elements of cultural models may extend across groups. Additionally, individuals may draw on multiple cultural models in different contexts and social interactions. Handwerker has advocated for a more general application of factor analytic procedures to assess inter-respondent correlation, or the construct validity of cultures (2002). Handwerker (2002), and Caulkins and Hyatt (1999), have shown that weak consensus, moderately high alternate factors, differentially distributed factor loadings, and negative factor loadings can all be useful data, and can signal cultural contestation, subcultural groups, and cultural 'turbulence.' So, they propose that rather than dismiss models that fail to meet the conditions of formal consensus analysis, these models can be interpreted in a more

general fashion, and can reveal important information about the distribution and coherence of cultural information.

Applications

Cultural consensus analysis has been successfully applied in several studies that specifically extra somatic assessed cultural beliefs about cancer, including understanding knowledge and attitudes about breast cancer among Latinas, Anglo-American women, and physicians (Chavez et al, 1995); cultural beliefs and the use of cervical cancer screening tests (Chavez et al, 2001); and influence of beliefs about the causes of cervical cancer and screening among Latina immigrants (McMullin et al, 2005).

In short, a theory of cultural models coupled with the analytic power of the cultural consensus model, enables anthropology to go beyond a purely qualitative conception of collective meaning, and “it frees us from simply assuming that we are discovering shared models of how the world works within a society. . .With this approach these constructs can be made operational” (Dressler, 2005, p. 26).

The cultural consensus model has important implications for the number of informants in a study. With this approach, it is not necessary to have large samples to objectively ensure the confidence of the responses provided. The model is sufficiently well defined and has stringent enough assumptions that stable results can be expected with a half-dozen or so informants in areas of high agreement (Weller, 2007). This is the first

time, according to Romney et al., that there is the ability to defend at the formal mathematical level the use of such small samples for the aggregation of cultural knowledge (Romney, Weller, & Batchelder, 1986). This approach is especially important when working in smaller tribal/cultural groups where the reliability and validity of health related research is often challenged when working with small numbers. On a theoretical level, “the model from a consensus analysis transcends individual explanatory models and is, in essence, an explanatory model at the level of the community – with systematic assessment of variation and statistical evidence to support the description” (Baer, Weller, De Alba Garcia, & Rocha, 2004, p. 18).

The use of the cultural consensus method and analysis represents a methodological step forward in that traditional ethnographic inferences can be tested more rigorously than previously. The linkage of cultural consensus analysis with survey data also represents a step forward, “because the way in which we move from ethnography to measurement is public and replicable” (Dressler, 1995, p. 30).

Cultural consensus analysis (Romney et al. 1986) provides a means of objectively measuring cultural knowledge. Using this approach, it will be possible to infer what the shared perspective on cancer is among YA community members, and from this propose appropriate ways to engage the community.

Methods and Sampling

This study consisted of three phases of data collection and analysis. For all phases of research, community members ≥ 18 years age, from the Yavapai-Apache (YA) community located in either, Camp Verde, Middle Verde, Rimrock, Clarkdale or Tunlil were recruited. The three phases of research consisted of: 1) defining the domain, 2) determining the existence of a shared cultural model, and 3) a survey phase applying ethnographic findings to the larger YA community. Each phase of research, its sampling and recruitment strategy and data collection and analysis procedures will be described in detail. A conceptual model of the overall study is illustrated below (Figure 10).

The Study Site

I chose to work with the Yavapai-Apache community, as a continuation of a working relationship from public health activities that began in 1999. I initially had contact with members from the community as a tribal liaison with Arizona regional tribes in ensuring the delivery of services by Indian Health Service (IHS) providers. Assistance was also provided, per their request, in the development and submission of grants for breast cancer awareness (2004). Additionally, an exploratory study was completed to determine cancer incidence from existing National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) cancer data specific to American Indians in Arizona through the University of New Mexico Tumor Registry for 1985-2000 in 2003.

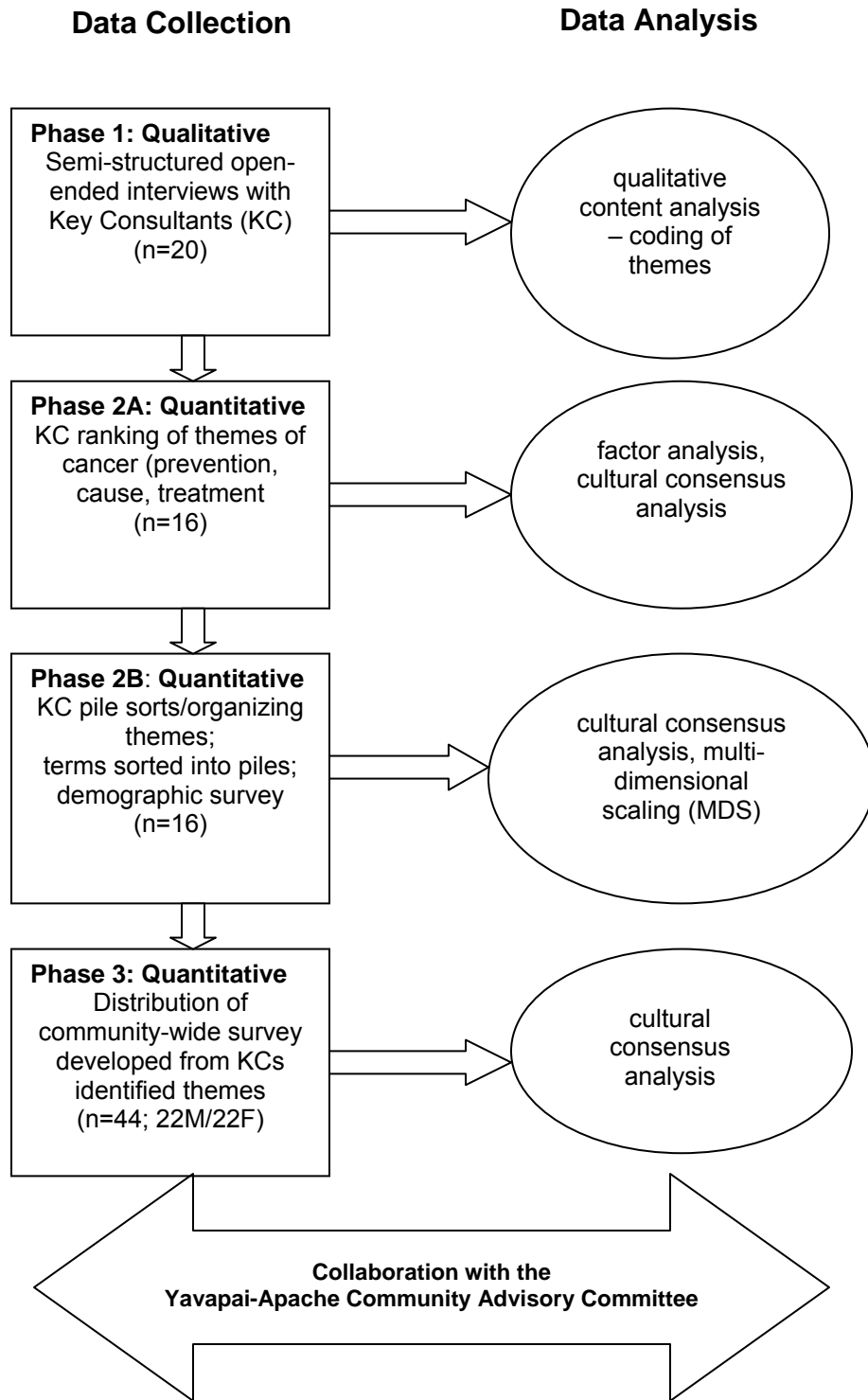


Figure 10 – Conceptual model of research study

The Yavapai-Apache community is located in the upper Verde Valley of central Arizona off of I-17, 90 miles north of Phoenix and 50 miles south of Flagstaff. The modern Nation is comprised of two historically and culturally distinct tribes both of whom occupied the Upper Verde prior to European invasion. The Western Apache group calling themselves, *Dilzhe'e* and known as the Tonto Apache utilized the lands to the north, east and south; while the Yavapai known as *Wipukyipaya* were using country to the north, the west and the south. It was the Upper Verde where they overlapped.

Under the Indian Reorganization Act, of 1932, the Yavapai and Apache people were officially recognized as sovereign people by the federal government. In 1992, under a revised tribal constitution, the tribe became known as the Yavapai-Apache Nation. Today, the reservation spans over five tribal communities including Camp Verde, Clarkdale, Middle Verde, Rimrock and Tunlii, and encompasses more than 1,600 acres throughout the Verde Valley. The descendants of the Yavapai and Apache people live in each of these communities totaling about 665 acres. The current total tribal enrollment of the Yavapai-Apache Nation is 2,289. Those enrolled tribal members that reside in the Verde Valley area number 1,083. The population is represented by 52% males and 48% females; 40% of tribal members are 17 years of age or younger.

Collaboration with the Yavapai-Apache Nation

Community-based participatory research (CBPR) principles were applied in the development and implementation of the dissertation research project. CBPR is an approach that is conducted as an equal partnership between trained researchers and members of a community. Equitable partnerships require sharing of power, resources, results, and knowledge, as well as a reciprocal appreciation of each partner's knowledge and skills at each stage of the project, including problem definition/issue selection, research design, conducting research, interpreting the results, and determining how the results should be used for action (Israel et al. 1998) The application of these principles would contribute to utilizing a culturally responsive and appropriate approach in collaboratively working with the community throughout the project, ensure active participation and mentoring of community members in the research process, foster community involvement and commitment to the study, and begin to establish future potential research partnerships within the community.

To ensure the involvement of the Yavapai-Apache Nation as an active partner throughout the research activities, a Community Advisory Committee (CAC) was developed in consultation with the Tribal Health and Human Services Department, the Community Health Representative Program and the Tribal Council. There were three members of the CAC, which included: 1) the Community Health Representative (CHR)/Women

Infant and Children's (WIC)/Diabetes/ Tobacco Prevention Program Manager, 2) the Clinic Manager of the Yavapai-Apache Medical Center, and 3) the Yavapai Culture Manager of the Cultural Resources Program.

The role and responsibilities of the CAC included providing assistance in: 1) the development, review and finalization of the research proposal, 2) the review and approval of consent forms, information provided to the community, community survey content review and approval, 3) review of updates throughout the progress of the project, 4) review of final analysis and results, 5) review and approval of the final report and presentations to be provided to the Yavapai-Apache Tribal council for their review and approval.

Research Approvals

As presented in the previous chapter, in 2004 the Havasupai Tribe of northern Arizona had filed a lawsuit against ASU and its Board of Directors, as well as three professor/researchers, charging the misuse of blood samples taken from tribal members (Shaffer, 2004). The case had not reached its conclusion and settlement prior to the submission of the dissertation research project for research approval from the Yavapai-Apache Nation and the ASU IRB. As a result, there were additional required research approvals needed to initiate the research project.

As noted in the 2009 ASU Procedures for the Review of Human Subjects Research, IX. Special Populations and Considerations, (F.) Native Americans (p. 31): "All studies recruiting subjects who live on tribal

land or that take place on tribal land will be reviewed by the University Advocate for American Indians. They may also be reviewed by an IRB member familiar with the subject population. Researchers must document Tribal Council approval or other appropriate tribal approval as part of the application process. All research conducted on Tribal Land involving Native Americans must be reviewed by the Full Board IRB except those studies that meet the federal definition as exempt.” The research review and approval process included: 1) the YA Tribal Council, 2) the University Advocate, and 3) the ASU IRB.

The University Advocate for American Indians

In consideration of the required levels of research review, an initial meeting with the University Advocate for American Indians was initiated in 2009 prior to formal ASU IRB review. I had already been working collaboratively with the CAC in the development of the research proposal and applying CBPR principles throughout the process. The purpose of the initial meeting was to request clarification of the criteria needed to enhance a positive IRB review.

Upon provision of the project abstract and summary, including the role of the CAC throughout the research project, the University Advocate indicated that the application of CBPR principles in working with the YA Nation was the appropriate collaborative model in addressing the IRB policy when conducting research with American Indian communities.

The Tribal Council

Following the final review, amendments and approval of the proposed research study by the YA CAC, a request was submitted to be included on the 2/25/10 agenda of the Yavapai-Apache Tribal Council for discussion and review. The action requested was the approval of a tribal resolution in support of the research study, which would then be submitted to the ASU IRB to indicate the YA Tribal Council's approval of the study to take place in the community.

All three members of the YA CAC were in attendance. Overall, the tribal council members were supportive of the research study and asked for clarification of different aspects of the proposed research, as well as directed questions to members of the YA CAC and the potential benefits to the health prevention, education and services currently being provided. However, the tribe's assistant attorney general raised specific concerns "about the ability of the Nation and its members to control dissemination and use of the information gained" from the research. Research issues related to the pending Havasupai lawsuit were specifically referenced.

The YA Tribal Council voted to support the research study, and approved the request of a tribal resolution in support of the study to be conducted in the community (Appendix A). However, the Tribal Council also indicated that an additional requirement needed to be met before any research could be initiated. They required that a written statement be provided from ASU stating that the YA Nation would have the opportunity

to provide final review of the information, results, findings and dissemination of the information presented resulting from the research and that the information shall remain the proprietary and confidential information of the YA Nation until the Nation determines otherwise.

Arizona State University

The research proposal with the supporting YA tribal resolution was provided to the ASU IRB for review and approval. The research study was considered exempt after review by the IRB pursuant to Federal regulations, 45 CFR Part 46.101(b) (2) (Appendix B).

Additionally, a letter addressing the additional requirement stated by the YA Tribal Council was provided from the ASU Office of Research Integrity and Assurance from the University Advocate/Special Advisor to the President, American Indian Initiatives (Appendix C).

Upon receipt of the letter, the YA Nation approved the initiation of the research study activities.

Informed Consent and Compensation

An informed consent form was collaboratively developed, reviewed and approved by the YA CAC. The final approved form was included with the research proposal for IRB review and approval (Appendix D).

Those who agreed to participate in the face-to-face key consultant interviews were provided a copy of the consent form prior to the interview. For many who had e-mail access and addresses, the form was sent for their review before their scheduled interviews. For those who did not have

internet access, the form was reviewed during the scheduled interview time before the interview. All participants were provided with a signed copy of the informed consent for their records.

A second version of the informed consent was developed for the community survey and provided to participants prior to their completing the survey (Appendix D). All survey participants also received a signed copy of the informed consent for their records.

Upon consultation with members of the YA CAC regarding appropriate compensation for the key consultant interviews and community survey participants, it was determined that appropriate amounts would be: 1) a \$25.00 gift card to a local department or grocery store for completion of the two scheduled meetings with the key consultants, and 2) a \$10.00 gift card to a local department of grocery store for completion of the survey.

Research Questions, Data Collection and Analysis

The goal of the proposed research was to apply a cultural consensus model to cultural knowledge and beliefs regarding cancer in the Yavapai-Apache (YA) Community located in the Verde Valley in central Arizona. Prevention and treatment of cancer in this community 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.

Understanding Yavapai-Apache knowledge and beliefs regarding cancer could potentially contribute to the development of a more culturally responsive cancer prevention education program that increases the frequency with which tribal members seek preventive cancer education and screening.

The specific aims of the research project were to answer the following questions:

- 1) What are the community members' knowledge and beliefs about cancer?
- 2) Do they believe it can be prevented?
- 3) Do they believe it can be effectively treated or cured?
- 4) What do they believe are reasons a person continues to live even after they are told they have cancer?
- 5) Is there cultural consensus in the YA community regarding the cause(s) of cancer?

The methods utilized to answer the research questions included both qualitative and quantitative approaches.

Phase 1: Qualitative Methods - Defining the Domain

Cultural anthropology has traditionally approached culture through narrative ethnographic methods and is concerned with the systematic, empirical study of the lived experience of communities. As a qualitative method ethnography provides a comparative, holistic study of cultural meanings and social relations through immersion in the community of

people being studied. The heart of ethnographic research consists of interviewing, in both structured and unstructured formats. It presumes that people (key consultants) possess valuable knowledge and beliefs that can be accessed through participant observations and in-depth interviews. Interviews, allow elicitation of the cultural meanings of a domain and individual narratives (Bernard, 2001; McMullin 2005).

The cultural consensus method combines qualitative ethnography with statistical factor analysis to allow dimensions of culture to be quantitatively operationalized, while preserving the richness of the ethnographic contexts.

Purpose, Sample and Recruitment

In the first phase of research, ethnographic interviews were conducted with key consultants (KC) from the YA community to elicit the possible themes or content that may define the cultural domain of cancer, including: 1) a description, 2) cause(s), 3) prevention, 4) diagnosis, 5) treatment(s), and 6) survival or living with cancer.

A non-probability method that utilized a purposive sample of experts was used in this study. This is consistent with previous cultural consensus research. As Handwerker and Wozniak (1997) have shown, the collection of cultural data, unlike individual level data does not require randomly drawn samples. Rather, when a cultural model is being defined, it is beneficial to draw purposive samples to maximize cultural knowledge

among the participants, so using convenience samples is acceptable (Handwerker and Wozniak 1997; Johnson 1990).

Assuming that a fairly coherent model exists, the number of subjects necessary to acquire a high level of validity is small. The lower the average agreement, the larger the number of participants there must be to maintain a specified validity level. Because there is no prior knowledge about the amount of agreement regarding the knowledge and beliefs about cancer in the YA community, a low competency score was chosen of 0.36 and stringent criteria for proportion of items ordered correctly (95% validity). Using these criteria, a minimum of 17 participants would be necessary and recommended to elicit the definition of a cultural domain (Weller and Romney 1988). In this study, variation in demographic factors that could affect the distribution of cultural beliefs, such as race/ethnicity, ages, and community of residence, were very low. As a result, twenty participants were determined as the number of participants for the first phase of research.

The CAC was asked to identify 20-30 community members who were considered by the YA community, to be leaders of influence – either positive or negative - but not necessarily elected tribal officials. Additional criteria considered for those selected to participate was:

- community members who reside in and are members of the Yavapai-Apache community;
- 18 years of age and older

- include both men and women
- individuals who have not been diagnosed with cancer
- family members of individuals diagnosed with cancer
- individuals who have had a cancer diagnosis.

An attempt was made to ensure distribution across age groups (i.e. ages \leq 18 - 30, 31-40, 41-50, \geq 51) and that the sample was a rough demographic representation of the community (i.e. marital status, SES, education). The individuals identified would be included as the group of key consultants (KC) for the individual face-to-face semi-structured interviews.

In discussion with the CAC, it was agreed that they would make the initial contact with the KC. A phone script was developed and approved to be used for the phone calls and contacts (Appendix F). After an initial effort by the CAC, it was noted that there was greater success in follow-up when the CAC reached the contacts directly and provided the information as opposed to leaving a message with the contact information. The KCs were asked if they would be interested in participating in the study. If they agreed, they were then asked if it was permissible for the researcher to contact them directly by phone and e-mail and then they provided their contact information. They were also provided with the phone and e-mail information of the researcher, if they wished to make the contact themselves.

The members of the CAC contacted 34 community members; 5 declined to participate; 9 did not respond after several efforts to contact and follow-up. There were a total of 20 who agreed to participate in the interviews.

Data Collection

The informed consent was either sent via e-mail to the participants, or reviewed prior to initiating the interview. In either case, the informed consent was reviewed before the interview and the participants were asked if they had any questions or would like additional information before the interview began. It was emphasized that their participation was entirely voluntary, that all information they provided during the interview would be kept confidential, and that they could decline to answer any questions at any time.

A set of questions was developed about various aspects of cancer. Weller (2007) has suggested that questions need to be clear and need to be understood in the same way by all the respondents. In further discussion, she indicates that for an illness, "questions can cover causes, symptoms, treatments, and so on." (2007, p. 349). As a result, a list of questions was developed in collaboration with the CAC and included: 1) a description, 2) cause(s), 3) prevention, 4) diagnosis, 5) treatment(s), and 6) survival or living with cancer (Appendix G). Although the list included 25 questions, it was often the case that because they were open-ended

questions, it was not necessary to ask each participant every question as they would provide the information without an additional prompt.

All interviews were conducted in Camp Verde, Clarkdale, Middle Verde or Rimrock. The interviews averaged 40 minutes, and ranged from 17 minutes to 72 minutes. All interviews were digitally recorded.

This method does not impose a set of beliefs on the interviewees. The interviewees themselves provided their perceptions or meanings from their own ways of thinking about cancer.

Qualitative Analysis: Determining Themes

After completion of the interviews and collecting the narrative to the questions, they were fully transcribed verbatim. Transcriptions were then verified by comparing the recording to the text. The transcribed texts were subject to line-by-line analysis, and research codes for each category were generated to index text that referred to specific themes. A qualitative data analysis software package was used to assist with consistent application of codes. The responses were analyzed by iteratively coding and categorizing data to uncover thematic categories (Glaser, 2007).

To determine which beliefs were most common, all responses were reviewed and analyzed to determine those mentioned most frequently. The responses were analyzed for the presence or absence of particular themes. After collecting the narrative statements, a cumulative list of the unique themes mentioned by all the informants is compiled. Then, for each narrative, the presence or absence of each theme is noted,

specifically, in a table where each row indicates a KC, each column refers to a specific theme, and cells in the table indicate whether a person mentioned a theme (1) or did not mention the theme (0). The presence or absence of themes can be analyzed to see the main themes (mentioned by a majority of informants), the agreement among informants, and the correspondence between each individual's themes and the main themes mentioned by the group (Weller, 2007).

All the remaining responses were reviewed to sift out the more individual beliefs, such as those listed by only one person. This process yielded two lists of responses for each question (i.e. shared responses and single/individual responses). A cumulative list of the unique themes identified by the KCs was compiled.

Phase 2: Quantitative Methods - Determining the Existence of a Shared Cultural Model

Purpose, Sample and Recruitment

The second phase of research and analysis considered to what extent the KCs agreed on the importance of the themes they have mentioned in the narratives. This level of analysis is based on research in cultural consensus analysis, which is related to determining the extent to which a group of people share "cultural knowledge" within a specific domain of culture (Boster 1986; Garro 1986, 1988, Weller and Romney, 1988, Weller et al. 1993).

The question of whether there is a single shared system of knowledge or shared cultural model for the domain of cancer can be answered by an analysis of the pattern of agreement (or variation) among the KCs. This pattern of shared knowledge (or agreement in the nature of the knowledge among people) reflects the patterns of transmission of that knowledge. Additionally, examining the disagreement among people can provide valuable insight into what passes for knowledge with a society, thus defining its culture (Boster, 1986).

To determine the relative importance of the beliefs about cancer for each individual KC, the systematic data collection technique of ranking, which have been shown to be effective in eliciting cultural models and the relative structure of items within cultural models (Weller and Romney, 1988) was utilized. Rank ordering has contributed to determining the extent of agreement among the KCs concerning the relative importance of the identified themes. This method does not impose a set of beliefs on the KCs. The participants themselves provided the themes, which came from the KCs own way of thinking about cancer.

To gain a better idea of the structure and content of the items in the culture domain, a pile sort was also completed with each KC. Weller and Romney (1988) recommend that once the cultural domain and themes have been identified it is important that the structure of the domain items be examined. Pile sorts can provide a monadic (Borgatti, 2002) item-by-item similarity matrix that can be examined with a variety of techniques.

Data Collection

At the first interview, and as was explained in the informed consent, the 20 KCs had agreed to complete a second interview. However, due to relocation or lack of response to the request for the second interview, a total of 16 KCs participated.

During the second interview, each individual was presented with a stack of approximately 15 index cards containing the shared identified themes from the first interview. They were asked to order the cards from “most” to “least” important as it related to domains of cancer. This approach was utilized with three stacks of cards with themes specific to the categories of: 1) prevention of cancer, 2) cause of cancer, and 3) treatment of cancer (Appendix H). As suggested by Romney and Weller (1985) and Bernard (2006), each set of cards was shuffled between KCs to randomize the order and so the order from the previous participant was not seen. The rank ordering allowed for the determination of the extent of agreement among the KCs concerning the relative importance of the themes they have previously identified.

After completion of the ranking task, the KCs were asked to complete a basic type of pile sort or “single sort” (Romney et al. 1979). Each participant was asked to sort index cards, with the identified themes on each card. They were asked to sort the cards into piles that they felt were more similar to one another. They could make as many or as few piles as they wished. This task was completed with the same set of three

stacks of cards utilized for the ranking task, with themes specific to the same categories of: 1) prevention of cancer, 2) cause of cancer, and 3) treatment of cancer.

A demographic survey was also completed that included information about tribal affiliation, culture and language, and general demographic gender, age, occupation, and other demographic information (Appendix I).

Quantitative Analysis: Determining Cultural Consensus

Cultural consensus analysis was used to test for the existence of a cultural model that would explain the KCs rank ordering of the themes (Romney, Batchelder and Weller, 1987; Romney, Weller, and Batchelder, 1986; Weller and Romney, 1988).

The informal cultural consensus model is utilized to analyze the rankings and assess the inter-informant (consultant) agreement patterns as determined by a correlation (agreement) of their rankings. This is essentially a principal components analysis (PCA) factor analysis of the key consultants. The factor analysis will indicate how much agreement there is among the KCs and the competence scores are an estimate of how much each participant agrees with the overall model (Weller 2007). The group rankings are then determined by averaging the rankings across individuals to determine the group response.

The resulting pile sort information provided by the KCs was imported into Systat (Wilkinson 2010). The program reads the data and

converts it into an inter-participant correlation matrix and then a PCA factor analysis was completed.

Phase 3: Quantitative Methods - Applying Ethnographic Findings to the Larger Community

Purpose, Sample and Recruitment

A survey was developed from the ethnographic findings of the consultant interviews to determine the extent to which the ethnographic findings are represented among a larger sample in the YA community.

The survey questions needed to be reasonable indicators of the beliefs regarding cancer. The goal was to develop 20 or more questions/items, at the same level of difficulty. The final questionnaire contained 60 questions to determine cultural consensus. The items were reasonable indicators of the shared beliefs and balanced in terms of their positive and negative aspects. The questions had enough variation in terms of developing questions posed to elicit both positive and negative answers, so that there would be variation in the responses (Weller, 2007).

The questionnaire was pilot tested for readability and content validity prior to distribution. This was accomplished by utilizing review and feedback from the CAC, tribal health department staff and Native community members. The final questionnaire also included inquiries about demographic characteristics and medical care access as well as knowledge, attitudes and practices related to cancer (i.e. preventive screening). (Appendix J).

Data Collection

To determine the appropriate sample size for estimating a proportion to within a specified margin of error for a finite population needed for the community survey, a power calculation of the eligible population was conducted utilizing software for sample size determination (Lenth, 2006). The confidence interval is of the form $p \pm ME$, where p is the sample proportion and ME is the margin of error:

$$ME = z * \sqrt{(p^*-p)/(n-1)}$$

where z is a critical value from the normal distribution, p is the sample proportion, n is the sample size, and N is the population size.

There is a population of approximately 969 that reside on tribal land in the Yavapai-Apache Nation community. However, 577 would actually be eligible to participate. For a 95% confidence level, and $p_i = .5$, the target sample size of participants was 94 individuals. Those eligible to participate were members of the Yavapai-Apache community; 18 years of age and older; who have not been diagnosed cancer, family members of individuals who have been diagnosed with cancer, and cancer survivors.

Community outreach to solicit participation was completed in collaboration with input from the CAC. A notice was posted in the tribal newspaper; posters were placed in tribal offices; a notice was distributed through the human resources department with tribal employee's weekly check distribution; and a notice was sent through the tribal e-mail system. The scheduled times for outreach to complete the survey was included, as

well as various locations, and included: the tribal administration complex, the Clarkdale Senior Center, the Middle Verde Senior Center, and the Wellness Program/Food Program. Participation was voluntary. All participants' identification and responses were kept confidential. An appropriate informed consent form was provided for completion by each participant and each was provided with an additional copy for their records.

There were a total of 74 YA community members who completed the survey, including 11 of the original KCs who were initially interviewed. The cultural consensus analysis was completed on a sample of 44, taken from the total sample of 74. There were 22 men in the complete sample who were case matched with 22 women of similar age. This approach enabled control for two variables (i.e. gender and age) and would allow additional analysis if needed. The demographic information from the remaining sample of 30 women would provide valuable descriptive characteristics of the larger representative community sample.

Data Analysis

A cultural consensus analysis (Weller & Romney, 1988; Romney et al., 1986, 1988; Weller, 2007) was used to determine if a shared set of cultural knowledge and beliefs was present in the Yavapai-Apache community then provide an estimation of that information. The cultural consensus analysis provides estimates of the culturally correct answers and estimates of individual differences in the accuracy of the reported

information as provided by the survey (Weller, 2007). Consensus analysis provides a means to evaluate the agreement among participants and to optimally aggregate their responses. Given a series of questions on a single domain, each individual's "cultural competency" regarding the set of questions is estimated and then, the competency scores are used to "weight" the responses and obtain a Bayesian confidence level for each answer.

The next chapter provides an overview and discussion of the ethnographic results of the key consultant interviews.

CHAPTER 5

VOICES FROM THE COMMUNITY: ETHNOGRAPHIC RESULTS

But like I said, cancer it's-- to me it's uncommon. . .because we were never aware of that, I would think, until maybe years later . . . I guess it's coming around in the Native Americans.

I think, she accepted (it) but she always used to tell us that "having cancer it's like. . .Indians don't get cancer." She used to say that, "Indians don't get cancer. Why did I get this cancer?"

Cancer and the impact it has had in Native American communities, is a fairly recent and unfamiliar experience. The diversity of cultures, locations, history and access to healthcare has influenced and framed the unique narrative and perspective of each tribal community.

I began working with the Yavapai-Apache Nation on public health activities beginning in 1999. My initial contact with members from the community was in the capacity as a tribal liaison with Arizona regional tribes in ensuring the delivery of services by Indian Health Service (IHS) providers. In 2004, the Director of the Community Health Representative (CHR) Program requested assistance in the development and submission of grants in addressing breast cancer awareness and prevention. The tribe was successful in their initial efforts and acquired the resources to begin providing mobile mammography services at the tribal medical center. However, there was still a concern that adequate cancer prevention and educational information was not readily available to community members.

This research project was a continuation of these collaborative efforts in addressing the community's concerns about cancer. Community-based participatory research (CBPR) principles were applied in the development and implementation of the project. The application of these principles would contribute to utilizing a culturally responsive and appropriate approach in collaboratively working with the community throughout the project, ensure active participation and mentoring of community members in the research process, foster community involvement and commitment to the study, and continue to enhance future potential research partnerships within the community.

To ensure the involvement of the Yavapai-Apache Nation as an active partner throughout the research activities, a Community Advisory Committee (CAC) was developed in consultation with the Tribal Health and Human Services Department, the Community Health Representative Program and the Tribal Council. There were three members of the CAC, which included: 1) the Community Health Representative (CHR)/Women Infant and Children's (WIC)/Diabetes/ Tobacco Prevention/Wellness Program Manager, 2) the Clinic Manager of the Yavapai-Apache Medical Center, and 3) the Yavapai Culture Manager of the Cultural Resources Program.

The CAC played a central role in identifying the 20 key consultants who were considered by the community, to be leaders of influence – either

positive or negative – and were participants of the ethnographic interviews and information that was provided.

Description of Participants and the Community

Ethnographic semi-structured interviews were conducted to obtain information about the cultural knowledge and beliefs regarding cancer in the community. Ethnography is a set of research methods that can be utilized to explore cultural knowledge and beliefs, usually through qualitative analysis of in-depth interviews and participant observation. This method may also be used in systematic data collection techniques, as in rank ordering and pile sorts of interview data that allow for a quantitative data analytic method such as cultural consensus analysis (Chavez et al., 1995), which will be discussed in detail in the next chapter. Ethnography focuses on shared cultural knowledge and beliefs and does not assume that the researcher is aware of all the relevant issues. This approach is therefore useful for exploratory studies, such as this research project, and is designed to better understand culturally based knowledge and beliefs. The first step was to determine if there is a culturally defined domain of cancer and if so, how is it constituted.

Key Consultant (KC) Characteristics

Information for this chapter comes from semi-structured open-ended ethnographic interviews completed with 20 key consultants (KC) from the community, as described in detail in the previous methods chapter (Chapter 4). The interview schedule (Appendix G) was developed

in collaboration with the Community Advisory Committee (CAC) to elicit possible themes that may define the cultural domain of cancer, including, 1) a description, 2) prevention, 3) cause(s), 4) resource information, 5) treatment(s), and 6) living with cancer.

During the second interview with the KCs, a demographic survey was also completed that included information about tribal affiliation, culture and language, and general data such as gender, age, occupation, and other demographic information (Appendix H).

All interviews were conducted in English, and took place in the reservation communities of Camp Verde, Clarkdale, Middle Verde or Rimrock. There were 20 adults (>18 years of age), represented by 12 (60%) women and 8 (40%) men. The tribal population living in the Verde Valley (n=1,083) is represented by 57% women and 43% men, so the gender representation of the interview sample was a close representation of the tribal population. The youngest interview participant was 27 years of age and the eldest was 70 years of age. The mean age for the women was 49 years of age, and 48 years for the men. Within the tribal population (>18 years of age), 47% of females are between ages 18-35, and 54% of males are between the ages of 18-35. Although the mean ages of the interview participants was in the older age range than that represented in the tribal population, this may have been primarily due to the criteria of selection of the participants, as “leaders of influence” and could have been indicative of the selection of older individuals.

Although all the participants were enrolled members of the Yavapai-Apache Nation, each tribal member may culturally identify themselves as either Yavapai, Apache, from both tribes, or from other tribal communities (i.e. Hopi, Navajo). The participants primarily identified themselves as Yavapai (41%), Yavapai-Apache (35%) and Apache (24%).

All but two individuals indicated that they resided and/or worked in the communities of Camp Verde, Middle Verde, Clarkdale or Rimrock for 20 years or longer. The majority of the KCs (83%) stated they participated in cultural activities in the community. They identified some of these activities as: Sunrise dances, traditional blessings, Indian week activities, Exodus Day, the Gathering of the Pais celebration, social dances, and Elder Recognition Day.

The event known as Exodus Day or 1875 Removal -1900 Return Commemoration is an annual holiday of remembrance of the 1875 forced removal of an estimated 1,700 Yavapai and Dilzhe'e Apache from the Verde Valley to the Indian Agency at San Carlos, located 180 miles away (Braatz, 2003). The people were forced to march across the Mogollon Rim through winter-flooded rivers, mountainous terrain, and harsh weather under the direction of U.S. Army troops. Several hundred lives were lost, including many women, children and elders, as well as the loss of several thousand acres of treaty lands promised to the Yavapai-Apache by the United States Government. The Commemoration honors their subsequent return in 1900 to their homeland after 25 years of internment.

The event includes a commemorative walk and weekend of ceremony, traditional song and dancing, food and other activities. Another annual event is the Gathering of the Pais. It is an annual traditional cultural festival that celebrates the Arizona Pai communities, including the Hualapai, Havasupai, Fort McDowell Yavapai, Yavapai-Apache and Yavapai-Prescott tribes. The activities include four days of traditional foods, games, arts and crafts, birdsong and dance competition, the Pai naming ceremony and Pai Woman and Elder Pai pageant.

With regard to language, the majority of the KCs (47%) identified Yavapai as their tribal language, while the remaining identified Apache (24%) or both Yavapai and Apache (29%). Over half (54%) indicated that they have varying levels of ability in speaking their tribal language (i.e. very well – little), and the remaining stated they either did not speak their tribal language but had an understanding or did not speak or understand their tribal language (Table 1).

During the interviews, as well as discussions with other community members, participants indicated that there is a varied diversity of religious and spiritual practices. There are currently five protestant denominational participating KCs, 39% self-identified as Protestant or Catholic and 23% identified as practicing traditional tribal beliefs or are affiliated with the Native American Church (NAC). Additionally, 22% identified themselves as participants of both protestant and traditional practice. The remaining identified as other or none Of those who identified an affiliation with an

Table 1

KCs language spoken and level of ability

Language Spoken	Female (n=11)	Male (n=6)
Apache	2	2
Yavapai	4	4
Both	5	0
Level of ability		
very well	0	2
moderately well	3	1
little	1	2
*DS, understand	0	1
**DS	7	0

*DS, understand = "don't speak, but understand some"

**DS = "don't speak"

affiliation with a religious or spiritual practice, 76% indicated they were actively involved at varied levels (i.e. very involved, somewhat involved).

A majority of the KCs were married (47%) and had completed high school (95%). Many (30%) had continued their education to complete college degrees (i.e. AA, Bachelors, graduate). Additionally, a majority (88%) were employed and had an annual income of <\$30,000 (65%), with an average of 4 per household.

Knowledge and Beliefs about Cancer

When asked what some of the first thoughts that may come to a person's mind when they hear the word cancer, the KCs responded that their first thoughts were about death or dying:

. . .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.

There's no cure. You might have a chance, but not really. Death. . . most of the time, that's where it ends up at.

One individual shared their experience about seeing a doctor after receiving cancer screening results, a potential cancer diagnosis, and the very real fear of facing death and the impact it would have on their family:

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 . . . Then, when I went home, 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.

The shared concerns and fears associated with death and dying related to cancer were based primarily on the participants' personal experience. The American Cancer Society (2010) has stated that in the general population, men have a 1 in 2 chance of developing cancer (all sites) in their lifetime, and a 1 in 4 chance of dying from cancer; women have a 1 in 3 chance of developing cancer (all sites); and a 1 in 5 chance of dying from cancer. The experience of the 20 KCs who participated in the interviews was an exception to these statistics, as 19 of the participants had either an immediate or extended family member who had been diagnosed with cancer. One individual had been diagnosed with cancer, in addition to the loss of a parent to a cancer diagnosis.

Yeah, we know several people who've had cancer. . . They didn't live very long.

the doctor did talk with me . . . and told us that she had this kind of cancer. . . you would never think that somebody . . . especially in my family would get the cancer.

The feelings of fear that were expressed were related to the unknown nature of cancer as a new and unfamiliar disease to their family, community and culture. Many expressed that they lacked the knowledge and information about what it was or what it was doing to the body, or if it could be treated or stopped:

. . . what's happened is that, first of all, cancer was unknown among Indian people because they didn't have a word for that. So they would say-- if you had a sore throat, then there was a word for that . . . (says term) . . . you have a headache (says term) . . . there's an explanation for that. But there's no explanation for disintegrating cells. . . So then its interpretation is that it's actually probably poisoning of the blood, would be a rough translation of what cancer would be, is that it's a poisoning of the blood and that the body's deteriorating. . . they see that as very, very threatening to their life. But they don't understand it. So the least educated you are, the more apt you are to fear something that you don't know anything about. That's in any society.

Several participants described their understanding about the process of what cancer is doing to the body - it "eats you up" and can't be controlled or stopped:

It's a disease that your body it's just being like eaten away with these cells. And it just grows and it's there . . . I mean it's unpreventable because it spreads. Whatever the diagnosis it will spread and that's the way I see that.

Well, the other thing too is the common person really doesn't understand what this cancer is. Probably on the whole our tribal members think cancer is like that old game thing, Pac Man where he goes around "chooka-chooka-chooka-chooka." Because that's

what you hear, "Cancer eats you up." They think of cancer as something that is in their body that is . . . eating you up. They need to understand that cancer is the cell goes wild and doesn't eat anything, it just takes over. You know? What was common normal cells are now cancerous and they just explode.

One individual identified specific tribal beliefs related to talking about cancer or any association with it, and contrasted these beliefs with generational differences among younger members within the community:

. . . somebody that's older than 55 or 60 years old . . . comes from a very traditional background. . . when an owl comes to visit them. . . they say that there's going to be a death in the family. So when . . . some nurse is going to visit you and interview you about cancer, we're going to talk about cancer, they don't want anything to do with that, because the more you talk about it, then what happens is it becomes a part of you. And so that's a cultural thing that people are afraid of. . . Now a person that's educated and is probably very young, like somebody in their 20s and their 30s and 40s, and that's recently educated-- maybe just gone to college some or graduated from high school-- is probably more apt to say, "Well, it wouldn't hurt to have an exam."

Closely related to the expressions of death and dying were feelings of fear that the disease can "pick" anyone to affect, regardless of age, health, or social status. It can "just happen" and there is no means of controlling or preventing anyone from a diagnosis:

. . . it just makes you wonder, where and how and who . . . how do they end up with it? It's just like shooting at pin balls . . . it seems like that's what cancer does. It picks. It can be somebody healthy over here and the worst drunk over here, and yet, sometimes it will hit the low one or hit the other one. And that's why I just wonder, how is it that one has it and the other one doesn't?

. . . it's not a hidden death; it's really a silent death. You just don't know then, all of a sudden, it happens.

The Causes of Cancer

When talking about what causes cancer, the participants identified two categories of causation. These were identified as causes related to lifestyle choices, and those they identified as resulting from environmental exposures.

Most of the participants identified smoking or exposure to tobacco as a primary cause of cancer. One individual expressed concern about someone who had worked at the casino and questioned whether this may have potentially contributed to a cancer diagnosis:

It goes through my mind. I think how . . .this person worked at the casino when it first started. There's smoke. You inhale that smoke and it even bothers me . . . when I go there . . . we take the elders there for a luncheon once a month and we're standing out in front there. I just smell it and it just bothers me. . .when I really sit at home sometime I think about things and I thought maybe that's how. . . that happened. I don't know. . .

There was a concern regarding tobacco use and its potential in causing cancer in a unique cultural context that was expressed by two individuals. Both regularly participate in traditional ceremonies in different tribal cultures held outside the community. Each discussed recent changes that have impacted an increase usage of commercial tobacco in traditional ceremonies, in contrast to the previous practice and use of traditional tobacco:

. . . these ceremonies that are conducted. . They use tobacco, for example, in their ceremonies . . . the medicine men are given tobacco, but it's not the traditional kind of tobacco that's harvested from the mountains. . it's a very smooth tobacco. It doesn't have any nicotine in it. . . So that's the kind of tobacco they used to use.

But today what happens is . . . they bring out the addictive, nicotine-filled cigarettes that have filter tips on them . . . to cut down on the cost of tobacco use, they buy the cheapest brand . . . which are kind of harsh too, they use those in the ceremonies. So the . . . men smoke them, and it's kind of an accepted way, when you show up, that you smoke a cigarette. Even the nonsmokers. . So the cigarette man's got a little basket that he carries around and it's strapped around his neck. . and he carries around a basket. Those are filled with those cheap cigarettes. . . But the thing with this is, is that when you're a man and you go into the ceremony, you smoke, you're sitting with the medicine man and the cigarette is passed to you, you're obligated to smoke. . .You cannot say, "Well, I don't smoke." . . Well, that's what white people do. They go, "No, tobacco causes cancer." . . No. When they pass the basket, people reach in there. . When the cigarette is passed to them, they have to have a cigarette, so they take it out and smoke it. . . So now you're at a ceremony for three days, and by now, when the ceremony's over with, you probably alone have smoked over 30 or 40 cigarettes. More than a pack, because there's 20 in a pack. So you probably maybe smoked two. I've done it myself.

A concern stated by many of the participants that they related to cancer causation was lifestyle behaviors or choices of diet or the type of foods that were eaten. These were concerns about community members eating too many fatty or junk foods and not eating enough fresh fruit and vegetables.

One of the most prominent concerns stated by participants was regarding cancer causation related to potential environmental exposures. As previously discussed in the background chapter about the community, the three identified sources were: 1) the cement plant, 2) the Phelps Dodge copper mine, and 3) the impact of nuclear testing that took place in the 1950's in Nevada and the "downwind" effects to residents of the Verde Valley.

The cement plant was built in 1959, and was a primary supply source for the construction of the Glen Canyon Dam. Upon completion of the dam in 1964, it was thought it would be decommissioned, however, the company continued to generate interest for other projects and it has been the primary supplier of cement to Northern Arizona and Phoenix (Beach 2009). The Salt River Pima-Maricopa Indian Community bought the plant in 1987 and still owns it today.

Many of the participants are concerned about the community's exposure to dust and residue that originates from the cement plant and the possibility that these particles may be causing cancer:

. . .the cement plant down there. . . We got a petition down there in Clarkdale . . .and I went to the town council. . . . fought with it and now we have the Clean Air Act. They're not allowed to burn but they still do. Not only that, I keep telling the council that they're still letting out something out of that plant and I said only way I can tell is because my windows, my windshield windows, you can see all this tiny little things. Like. . . a dust storm going into California. . .

Another participant stated the belief that a relative's cancer diagnosis was related to living in the community adjacent to the cement plant:

I remember when I think she was in tenth grade then and she would say, "I think I'm getting cancer. I think all of us are going to get cancer because of the cement plant that they put up," and they had been telling stories out there that people were going to get cancer from this if you lived in the area

As stated previously, there has been cause for concern over the past decade related to the history of the mining industry in the Verde Valley and the resulting environmental pollutants and possible relationship

to higher cancer rates. The Verde Valley was the home of one of Arizona's largest copper mines, the Phelps-Dodge mine at Clarkdale. Copper mining began in 1865 and continued until 1948. When operations ended, the smelter was closed and the site abandoned (Foust et al., 2004).

The participants voiced their fear that exposure to residual environmental pollutants generated from the mine increases the cancer risk to the community:

. . . a lot of the elders. . . when the smelter was going and the mines . . . said that you couldn't see Jerome for the amount of cloud and dust and stuff. You couldn't see up to the hill because of the smelter and the smoke and all that stuff going on . . . So, to me, I think the things, like, you know, the mine. . . those leach ponds that are up there, the water that's down here, the things that these people have breathed and things that have to be in the soil and how that has to affect our bodies somehow. . . it can't be real, real good for us.

The most commonly identified environmental exposure that participants believe has contributed to an increased rate of cancer among community members are the "downwind" effects from nuclear testing in Nevada that occurred in the 1950's. There were individuals who stated they knew of some type of "air pollution" they had heard was possibly causing cancer. There were several who had relatives or knew of community members or families who were recipients of compensation awarded from the federal government as a result of the Radiation Exposure Compensation Act (RECA):

I think (it) was just found out recently that this pollution of some sort . . . caused the cancer among the Indian people here, but I don't think there's really been any information . . . to indicate that this is

something that we should be concerned about, that people should be examined for, if they lived all these years here, like I have. So I've been here since I was 3-years-old, and so that's in the '40s, so I don't know. I know recently they did some sort of study, but, to this day, I don't know if there's that study still going on.

. . . all of us have been here. . . the study that they were doing on that pollution, it seems like no one's doing anything about it. . . we had that young gentleman that passed away and then this girl and it just seems like, when other things have popped up, 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. So how many people are affected? 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 because you try to detect some of the things that you might have, the ways that it affects a person.

During follow-up questioning with those who were familiar with the RECA program, the participants were not aware of any efforts to notify community members that they might be at higher risk and should be screened for cancer. The purpose of the outreach in the community by the compensation program was focused on those who had already been diagnosed or had relatives who had died from specific types of cancer and the financial benefits they may be eligible to receive.

Cancer Prevention

When the participants were asked if cancer could be prevented, there were many (55 per cent) who did not think it could be prevented, and believed that it "just happens":

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.

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

There were an equal number of individuals who, although they were not aware of any way to prevent cancer, stated their concern that more education was needed for community members regarding early detection and treatment:

I just always thought cancer appeared in you no matter what. I think one of the important things I think is what we need to do is educate all families that there's a possibility that somebody in the family can have cancer. We just need to be educated more on the disease so we understand it a lot better and if things do happen within the family they know what to do. Not wait too long for it, or they know they need to regular checkups, you know, both women and men.

Those KCs who discussed ways they believed cancer could be prevented described two categories, 1) medical resources, and 2) lifestyle changes.

The medical resources identified as possible means of preventing cancer were regular checkups, as well as having needed cancer screening tests. The screenings that were specifically identified included mammography, pap test, prostate screening, and colonoscopy (Mammography and pap tests have been provided by the tribal health center):

There's certain things you need to have at your check up. . .check certain things within your body that if there's a lump or something like that you need to go ahead and go to the doctor and check it out or you need to go ahead and get your regular, what do you call your test, especially for women.

The lifestyle choices or changes that participants identified that prevented cancer included abstaining from tobacco use, increasing exercise activities and eating a healthy diet, including fresh fruit and vegetables.

A couple of individuals said they believed that one of the reasons there is more cancer in the community is that living a traditional lifestyle of more exercise (i.e. walking) and traditional foods is less common, although the cultural resource programs (both Yavapai and Apache practices) are making efforts of reintroducing several of these activities back into the community:

People back then they did a lot of their planting. They planted their own food and they lived off of their food. During the summer time, they would plant-- my dad was like a farmer, he planted . . . down here on Little Verde on the reservation . . . he had a big farm. . they did a lot of canning too. . We had peach trees . . . so we had that as like a dessert during the winter time. . . then there are certain times that they would go out besides farming they would get the acorn and the piñons and walnuts. My dad used to go get us walnuts, pick walnuts and dry them out on a canvas because they were green and dry them out. . . And we used to eat walnuts and deer meat. We had a lot of deer meat. He'd go hunting every year so that was our meat part. . .we'd have meat every once in a while. But back then . . . the food part, I mean the lifestyle and the food. When you look at those stuff compared to now, like my children didn't really have much of that . . . And the other one was . . . They had the red berry juice. . . They picked it out here . . . the red berry . . . its sour. . . But you grind them, you make like they call it a Kool-aid, the Indian Kool-aid. . . But that was the drink they gave us. But talking about the lifestyle, the food, it's what you were brought up with and what you've had.

Knowledge about Cancer Treatment

When the participants were asked if they could talk about ways used to treat cancer, a few participants talked about surgery to remove the identified cancer. Almost all mentioned either chemotherapy or radiation treatment. However, when asked to describe what these 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, and described the effects that often included fatigue and hair loss experienced by the person being treated:

. . .it's a battle for your life. And then the chemotherapy, they put the poison into you that makes you sick, but at the same time it's fighting the cancer cells, so you got to trade off that evil for an evil and hope this one wins.

For many it brought up difficult memories of what they had personally experienced when caring for a relative or loved one:

At the time I thought it was a way to cure her, to take all that away and just kill whatever this cancer was and I was hoping for that. But it didn't, it didn't. So later on I figured, well that was just like it was giving her-- they were trying to give her more time, it's like recession (remission) to kind of keep her around a little longer. So after I learned these things-- and that's what I hoped for too also was that this would work in that way. . . But I do remember her being really sick after that and it was like all her strength was gone after those treatments. And I'm sorry to say it, but her hair had fallen out also. That's what I noticed and it was really sad at that time to see that.

There were very few that spoke of their knowledge of family or community members who utilized traditional providers or ceremonies as an option for treatment. However, two individuals did speak about the use of specific plants or herbs they knew had been used for treating cancer:

. . . one of the plants grows here. It's called the greasewood, or the chaparral. . it means "sticky plant", I think is what it means. And it's a green bush that grows all over, all the way down to Phoenix, by the side of the highway. And you boil that. And that is supposed to cure everything. . . it's known to have a number of cures. So it opens up the blood vessels, it's good for circulation and also it's good for numbness and that kind of thing, cleaning out the kidneys and all that. So . . .today. . . people here too still boil that. Some of the traditional people even drink it.

Another individual mentioned knowledge of a community member who incorporated the use of the sweat lodge for treatment after receiving a diagnosis of cancer:

He said he was doing, you know, sweats or he changed his eating or stuff like that and wanted to, in a sense, kind of heal himself and had said that, you know, it was actually better for him. He was feeling better, almost to the point where he, like, refused to go back to the hospital to see if anything was happening with it because he was feeling better. . . . I'm not sure if he was helped by anyone or if he kind of just did it on his own . . . I know that there are sweats that people participate in and cultural things that they do. I don't know if there's any one particular person or avenue that they would take. I guess it's all different for everyone.

Does It Ever Really Go Away?

When the participants were 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. A few individuals

mentioned the possibility of miracles that can occur because of their faith in God:

There's miracles. When you pray with God and He's with you, it happens. It happens.

The remaining KCs 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 . . . because 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.

The majority had knowledge of what it meant for cancer to be in a state of remission. But several stated they believed that the cancer was only "asleep" or "dormant" and could become active again without warning. An experience was shared by a participant, of a discussion with a doctor upon finding out that a family member's cancer had returned following a period of remission:

I think that it's gone forever. And then all of a sudden, they say it's back. I said, "Wait a minute. I thought you said they were cured." "No. What we should have said. . (was) it was in remission." "Oh, so in other words, it goes to sleep but then it wakes up whenever it feels like it." "Well, something like that." Well, no. That is exactly what it is. But don't tell me they're cured. Just say that it's asleep, and just hold your breath that it doesn't wake up.

Living with Cancer

As previously mentioned, 19 of the KCs knew a family member who had been diagnosed with cancer. 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, 1) a change in lifestyle, 2) ongoing treatment and medical care, 3) support from family and friends, 4) their attitude, and 5) the strength of their faith or spirituality.

When people spoke about a change of lifestyle and its influence on extending the life of individuals living with cancer, they referred to efforts to be active and eating a healthy diet.

Continuing or seeking ongoing treatment was also mentioned by several participants. One individual mentioned the experience of a family who sought and received an experimental treatment or clinical trial that was available at an oncology clinic in Sedona. Those who receive oncology care access specialty care at Cottonwood, Sedona, Flagstaff or Phoenix. Some have received care through the Indian Health Service (IHS) at the Phoenix Indian Medical Center, where oncology services are provided by the Mayo Clinic.

Many participants emphasized the importance of the support that cancer survivors needed from family and friends:

. . . when family and friends . . . come in . . . that makes a big difference to help support them, give them more support because if they know they're down, they know it's going to be a rough road to get them going again.

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 Verde Valley Medical Center located in Cottonwood, a 30 minute drive from Middle Verde.

Over half of the participants stated that they believed that the person's attitude about living with a cancer diagnosis would greatly impact their ability to live a longer life:

. . .one of the biggest aspects is the mindset. If you already know you got it and you believe, "All right, I won, I beat the battle," even though it's still in you, that's a number one way to actually survive it I think because you already-- you didn't give up and keep going and you're strong and you're more than willing to take any obstacle that comes your way and just live through it, live your life out happy as can be still.

Many also emphasized that one of the most important influences in maintaining a positive outlook and attitude was the role of spirituality and/or faith in God. The use of prayer and reading the Bible were also mentioned as vital in providing support throughout a cancer survivor's journey:

So I think the people that really continue to live through it and live with it and live a life of optimism because of their faith, spiritually grounded, I think that we . . . always say "think good thoughts." We're always optimistic. If you're pessimistic, that's when you're in trouble. As my mother used to say, "you have to beat this thing. You never give into it." . . . I think their spiritual life has a lot to do with how they live with it. They just have that fortitude

. . .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.

Resources for Information and Needed Education

Throughout the interviews, individuals identified the resources they accessed to find out general information about cancer, specific treatment options and screening information. Most identified their doctor or medical facility, including the tribal health center, as sources of cancer information. Others stated they had received brochures, and accessed information through the internet when they had questions. There were also many who stated that they had received information through tribal programs and at specific cancer awareness events held in the community (i.e. walks, conferences).

However, almost all the participants expressed their concern that the community lacked needed information and resources related to their concerns about environmental exposures, prevention information, treatment options, and support services for cancer survivors and their families.

One person expressed hope that through the provision of needed prevention programs, screening, treatment and support services that the experience of cancer would change for the next generation of tribal members:

. . . even today I think about that. . . I think about my grandkids also, because I have a lot of them. . . that things like that don't affect

them. I hope they don't get this kind of disease and I hope the medicine today, they've improved on it so that they can at least, if they do, hopefully they don't, but if they do that they can live a long time too also. That's my hopes anyway. Having had these kind of experiences, I'm able to say these things, it was something very close that happened, it wasn't good.

Summary

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

The community's knowledge and experience of cancer has been one of late diagnosis and very little experience or knowledge of community members surviving and living well after a diagnosis. Most acknowledged that they don't know if cancer can be prevented and lack current health education regarding: the prevention of cancer; the availability of cancer screening tests and why they are needed on a regular basis; what successful treatment options are available; and awareness of what support services or programs are available to cancer survivors and their families.

During the interviews, the participants expressed concerns they had about what they thought might cause cancer. The types of causation they identified could be divided into two categories: 1) environmental and 2) lifestyle or behavioral. However, although they identified what they

believed may cause cancer, the majority of participants didn't believe cancer could be prevented.

How can this information be utilized to respond to the concerns about the causes of cancer expressed by the participants? By addressing these concerns of causation, will it increase the possibility of preventing cancer in the community? Are these valid concerns and if so, what can be done?

The primary environmental concerns were related to exposure to possible chemical or toxic substances from the cement plant (i.e. residue dust and particles) and the Phelps Dodge copper mine (i.e. tailings, leach ponds). This is a valid concern that has been expressed by community members. It has been well documented that a public health issue that is currently confronting the Southwestern region of the United States is the exposure to hazardous waste, specifically arsenic, chlorinated hydrocarbon, and mine tailings contamination due to the extensive history of mining in the state (UA, 2008). Mine tailings cover 300,000 acres in Arizona alone (UA, 2008). A suggested first step in responding to the community's concerns would be to contact the Superfund Basic Research Program (SBRP) at the University of Arizona. It is a multi-university program supported by the National Institute of Environmental Health Sciences (NIEHS), which is one of the institutes at the National Institutes of Health (NIH). The SBRP's stated underlying research is "detecting, assessing, and ameliorating environmental pollution and determining the

impact of environmental pollution on human health” (UA, 2008). The program could be contacted to inquire 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. If that is not a function of the program, they may be able to provide a referral to resource agencies or programs that could provide similar assessment services.

A second environmental exposure concern was related to the impact of nuclear testing that took place in the 1950's in Nevada and the “downwind” effects to community residents. As stated previously, there were several participants who were aware of community members or their families who have received compensation through RECA due to a diagnosis or death due to cancer. Although the exposure to radiation due to nuclear weapons testing in Nevada is a known cause of cancer in the region, there has been little or no emphasis by the RECA program to provide education to community members on the importance of seeking annual cancer screening, or providing an awareness of possible symptoms that should prompt them to seek immediate medical care. A cancer education program needs to be developed that specifically outreaches to the senior or elder population and their families providing educational information, including available cancer screening resources.

The lifestyle or behavioral causes of cancer that were identified by community members (i.e. tobacco use, diet, exercise), actually should be framed within a prevention education message of risk factors to be

avoided and/or preventive behaviors that should be practiced. The National Cancer Institute (NCI) states that diet is being studied as a risk factor for cancer (NCI, 2011). Research has shown that poor diet and not being active are two key factors that can increase a person's cancer risk. It also increases the levels of overweight and obesity. Recent studies have shown that obesity has been linked to a higher risk of certain types of cancers, including: colorectal, endometrial, esophageal, kidney and pancreatic (NCI, 2011).

The prevalence of obesity among different tribes has become widespread, as well as the increasing prevalence of diabetes. Recent research has indicated that the ongoing epidemic of diabetes within Native American communities has become an emerging risk factor for developing cancer (Larsson and Orsini, 2005; Richardson and Pollack, 2005).

An effective approach to providing cancer education and prevention information to the community may be to integrate a prevention message within the already existing diabetes prevention curriculum and activities. 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.

Recent research has shown that disparities in use of preventive services, and access to care contribute to disproportionate burdens of cancer among racial and ethnic minorities, low-income groups, and other

underserved populations (Steele et al., 2008). Studies have shown that these disparities persist for the AI/AN population (DHHS, 2009).

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 would the expense of the screening be paid (i.e. IHS, tribal insurance, private insurance, etc.).

With regard to treatment options, the participants indicated a familiarity with the types of treatment (i.e. chemotherapy, surgery, radiation), but most had a limited knowledge of what was the purpose of the treatment, especially since many believed there was no cure, or that few would survive a cancer diagnosis.

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.

CHAPTER 6

CULTURAL CONSENSUS ANALYSIS AND RESULTS

The overall aim of the research study was to determine if a cultural model of cancer existed in the Yavapai-Apache community. A community-based participatory research (CBPR) approach was utilized when applying a cultural consensus method in identifying the collective knowledge and beliefs about the prevention, cause(s), treatment, and survivorship of cancer.

Three phases of research were undertaken: 1) ethnographic interviews – identifying themes or the content of the participants' cultural model, 2A) ranking of themes – understanding the relative importance of the content of the cultural model, 2B) pile sorts – the organization of items within specific domains, and 3) community survey – whether the model is shared in the greater community.

The last chapter focused on the results from the qualitative results of the ethnographic interviews. In this chapter, the quantitative analysis and cultural consensus results are presented. The final chapter will focus on the presentation of the importance of both the qualitative and quantitative results, the implications of both and the potential importance they may have on the community's approach to addressing cancer.

Phase 1: Identifying the Content of the Cultural Model

In the first phase of research, ethnographic interviews were conducted with key consultants (KC) from the Yavapai-Apache (YA) to

elicit the possible themes or content of the cultural domain of cancer, including: 1) a description, 2) cause(s), 3) prevention, 4) diagnosis, 5) treatment(s), and 6) survival, or living with cancer. The interview schedule was developed in collaboration with the CAC (Appendix G).

A non-probability method that utilized a purpose sample of experts was used in this study. The CAC was asked to identify 20-30 members who were considered by the YA community, to be leaders of influence – either positive or negative – but not necessarily elected tribal officials. The members of the CAC contacted 34 community members. Through follow-up and contact there were 20 participants who agreed to participate and completed the ethnographic interviews.

The interviews were audio-taped and transcribed, and analyzed using MAXQDA (VERBI Software 2010). It is a software program designed for computer-assisted qualitative data, text and multimedia analysis. I analyzed the interviews to create codes that people used when talking about cancer. The initial coding resulted in 845 items in response to the questions asked during the interview and included items specific to descriptions of cancer, cause, prevention, treatment, and living with cancer. MAXQDA has the ability to create a code matrix browser (CMB) that offers a visualization of the codings made in each document. One can then easily see which codes are used often (or rarely) in each document (See the codes in Appendix K).

The items were organized in broader categories as determined by the list of key consultant interview questions (See the Interview Schedule Appendix G), that were developed in collaboration with the Community Advisory Committee (CAC) and included: 1) a description of cancer, 2) things that increase risk or cause cancer, 3) what may prevent cancer, 4) sources of information about cancer, 4) treatments for cancer, 5) possible ways to make cancer go away permanently, and 6) beliefs or behaviors that enable people to continue to live after a diagnosis with cancer.

The items in each category were sorted according to their group/subgroup frequency. Romney and Weller (1988) indicate that there is no “hard and fast rule about how many items” (p. 25) to use to conduct a pile sort, although in general 20 items are often used (Bernard 2006). All the resulting items from the categories identified were included in the pile sorts to reach the 20 items per pile sort (see Appendix H). The resulting categories included: 1) prevention (n=14), 2) cause (n=17), and 3) treatment (n=12). Additionally, the categories were divided into two lists, based on what items would be used in Phase II - rankings and piles sorts (Appendix L), and Phase III - the community survey (Appendix L and M). The basis for this approach is that rank order methods require participants to “rank items in terms of a specific characteristic “(Weller and Romney 1988, p. 43). Because some of the categories were more descriptive (i.e. cancer descriptions, living with cancer) rather than the identification of characteristics of cancer (i.e. prevention, cause,

treatment), these items were utilized in developing the questions for the community-wide survey (Appendix J).

Phase 2A: Ranking – Content Importance of the Cultural Model

To ascertain the relative importance of the items in each category, each item was printed on an index card and the KCs were asked to rank order them from most important to least important.

Sixteen individuals from the twenty key consultants who were interviewed participated in the ranking. The items were ranked in three separate categories: 1) the prevention of cancer (n=14), 2) the cause of cancer (n= 17), and 3) the treatment of cancer (n=12). The list in Table 2 provides the items that were ranked in each category. This rank ordering procedure allowed for the determination of the extent of agreement among the KCs concerning the relative importance of the items for the prevention, cause and treatment of cancer.

This method does not impose a set of beliefs on the participants, as they themselves provided the items during the ethnographic interviews and they came from their own way of thinking about the different categories related to cancer. For example, within the category of prevention, the item “age” was explained as related to older members of the community who may have lived a healthier or “traditional lifestyle” of traditional diets and more exercise that may prevent them from getting cancer as a result. Additionally, “breastfeeding” was also identified

Table 2

Ranked Items

Cultural Domain Items	
Prevention	age avoid alcohol use breastfeeding avoid chemicals diet drink a lot of water education exercise avoid exposure to the sun heredity avoid sexual intercourse avoiding soda pop avoiding tobacco use Yavapai-Apache lifestyle
Cause	age alcohol use lack of breastfeeding cement plant exposure to chemicals diet downwinders (nuclear testing exposure) lack of drinking a lot of water lack of education lack of exercise exposure to the sun heredity mine/smelter sexual intercourse soda pop tobacco use lack of Yavapai-Apache lifestyle
Treatment	attitude check-ups chemotherapy herbs/plants hospice medication prayer radiation spiritual belief surgery traditional ceremonies traditional practitioner (medicine man)

as a means of preventing cancer, based on information provided from a health program.

The informal cultural consensus model is utilized to analyze the rankings and assess the inter-informant (consultant) agreement patterns as determined by a correlation (agreement) of their rankings. This is essentially a principal components analysis (PCA) factor analysis of the key consultants. The factor analysis will indicate how much agreement there is among the KCs and the competence scores are an estimate of how much each participant agrees with the overall model (Weller 2007). The group rankings are then determined by averaging the rankings across individuals to determine the group response.

The first step in the analysis was to create a correlation matrix to identify any agreement patterns between people based on their responses to the rankings. The informal cultural consensus model is essentially a factor analysis of people's responses. Individuals are used as variables (columns in the data matrix) and their responses (rows in the data matrix) are used as cases, whereas typically individuals are cases and their responses are the variables (Weller and Romney 1988). The factor analysis for consensus was run in Systat (Wilkinson 2010).

Cultural consensus is said to exist when the ratio between the eigenvalues of the first factor is three times larger than the second factor or greater, indicating a single factor solution. In spite of variation among individuals in answers, if there is a single pattern of answers, the ratio of

the first and second eigenvalues will be large. The factor loading is a correlation of each respondent with the underlying pattern of cultural knowledge about the domain. Therefore, if the factor loading of the first factor is less than three times the loading of the second factor, then the results indicate the presence of more than one cultural model and the consensus model does not apply (Weller 2007).

The results of the consensus analysis concerning the consensus within the group of KCs about the three ranked categories of cancer are given in Table 3. Each ranking results is discussed in the following sections.

Table 3

Consensus Analysis of the Three Rankings

Ranking of	Sample	n	1st to 2nd Eigenvalue ratio	% of total variance explained by 1st factor	n with negative 1st factor
Prevention					
	women	10	2.37	42.474	1
	men	6	2.00		0
	Total (w CHR)	16	2.74		1
	Total (w/o CHR)	14	2.938		1
Cause					
	Total (w CHR)	16	2.917	47.013	1
	Total (w/o CHR)	14	3.687	51.072	0
Treatment					
	Total (w CHR)	16	1.83	44.523	0

* w CHR = with community health representatives

** w/o CHR = without community health representatives

Prevention

There is no consensus overall on importance of concepts of prevention. There was one individual with a very small negative first factor (-.029). However, the ratio of the first to second eigenvalue was 2.74 for the total KC sample (n=16).

It might be possible that by looking at gender differences by sorting, there could have been agreement amongst gender groups (i.e. women with women, men with men). However, when this was done there was still no agreement found among women or among men. The women were not agreeing, as indicated by the ratio of first to second eigenvalue ratio of 2.37. The men also had no consensus of agreement, with an eigenvalue ratio of 2.

It may make sense that there is no agreement in the rankings of prevention, not just in cancer but potentially for other illnesses also. Concepts of causes may be more concrete and firm so people may have very specific concepts of causes. Additionally, symptoms may also be something people will agree upon because they are experienced individually or they are visible, so people may know more about symptoms and causes than prevention or treatment.

The results could also indicate that the community has not received a prevention education message about ways to prevent cancer and may build a case for the need in developing or enhancing the public health information in cancer prevention.

Cause

Although the ratio of the first to second eigenvalues ratio was closer to consensus at 2.917, it still was not greater than 3.0.

However, when looking at the results, one person's results stood out as an odd case, with a high negative first factor value of -.0583. When reviewing the demographic information, it was discovered that this individual was a community health representative (CHR) who was included among the KC participants.

When a closer review and comparison of this individual's ranking results was compared to the remaining members of the sample (n=14), there was an indication that this person was emphasizing individual practices and behaviors as the most important cause of cancer, as compared to the remaining members of the sample who were ranking environmental factors as the most important contributors to the cause of cancer.

Community Health Representatives (CHRs)

As a result of these findings, follow-up interviews were completed with the community health workers to get a better understanding about their background and required training requirements, which may provide an explanation of the resulting differences in rankings and clarify the presence of different cultural models about the causes of cancer.

The mission of the Community Health Representative (CHR) Program is "to provide quality outreach health care services and health

promotion/disease prevention services to American Indians and Alaska Natives within their communities through the use of well-trained CHR's" (Indian Health Service 2010). When the program began in 1968, it was not a creation of the Indian Health Service (IHS). It was initially funded in 1967 by the Office of Economic Opportunity (OEO) as the Community Health Aide Program. In 1969, the IHS requested funds to train 250 Community Health Aides in Alaska and by 1972 the last OEO-CHR program was transferred to IHS, which increased its support and training of CHRs to 1,003 in FY '74. Although it is currently funded by the IHS, it is primarily a tribally contracted and directed program of well-trained, community-based health paraprofessionals, who provide health care and health promotion and disease prevention services, regularly visit homes of clients, conduct health assessments and provide transportation when needed in their tribal communities. Tribes have the flexibility to hire and design health care programs to meet tribal members health needs through coordinated care for community members in their homes. Currently, the program has grown to over 1,400 CHRs representing over 250 tribes in 12 service areas (Indian Health Service 2010).

During the follow-up interviews, the CHRs indicated that their initial training required attendance at a two week basic course provided by the IHS emphasizing public health and home care concepts and skills. They are required to attend a one week refresher training every three years to update their health care skills. They stated that the tribe also required

completion of CPR certification and certified nurse assistant (CNA) training.

When asked if they had been provided with specific cancer education and information during their training, one individual stated that it was not included as part of the basic course training, but had been offered as a workshop during the past year during the most recent refresher training, as well as a presentation during the national bi-annual CHR conference. In further discussion, they said that although they were required to attend the presentations, there weren't specific skills building training or resources provided to develop cancer education modules for their community. They indicated that the cancer prevention information that they have provided in the community has primarily been part of diabetes prevention messages focused on diet, exercise, encouraging breastfeeding, as well as part of the tribal tobacco prevention program.

Some background information that was provided that may also be relevant to the results was that the individuals did not live in the community. Both resided in locations 45 minutes to an hour away. They had also been employed as CHRs from 2-4 years.

The interview results and information regarding the required training and program information from the IHS provide a better understanding of the potential reasons behind the differences in rankings of the community and the CHRs. The community's ranking of important causes of cancer, as well as the results from the ethnographic interviews

discussed in the previous chapter, indicate that there is a strong emphasis and concern about the perceived causes of cancer that may be due to exposure to the cement plant, toxic waste from the Phelps Dodge mine and the exposure to nuclear radiation as “downwinders”.

In contrast, the CHRs are providing a public health prevention message focused on lifestyle change and based on the IHS training. They have not had specific training with respect to cancer and therefore could not deliver that information on causes and prevention to the community. Additionally, because they have been in their current roles for less than five years, as well as reside outside the community, they may have had limited awareness nor shared the community’s environmental concerns.

Weller has indicated (2007) that eliminating people from the sample can only be done under very careful or exceptional circumstances, and with full disclosure of the process and rationale. In this case, when comparing the ranking results of the CHRs with the rest of the KCs, they have a different rank order of the items they perceive as important causes of cancer. The CHRs emphasized the importance of individual behavior and responsibility, in contrast to the importance of environmental factors as causes of cancer expressed by the community. Review of the prevention agreement matrix indicates that the CHWs are agreeing in 25% (.25 in the correlation matrix) on their rankings of cause.

A cultural consensus analysis was completed a second time without the community health workers included in the sample (n=14).

Everyone in the sample has a positive and fairly large first factor, and no negative values. The ratio of the first to second eigenvalue was 3.687, indicating consensus or agreement on a very common cultural model of the importance of the cause of cancer.

Since there is consensus, there is justification then in taking the average of the rankings, as this provides an approximation of what people are in agreement on regarding the causes of cancer. Table 4 shows the cultural model of causation of cancer, and compares it to the ranking of a community health representative.

Table 4

Cultural Model of Important Causes of Cancer

Key Consultants (n=14)		Community Health Representative	
1.	chemicals	1.	diet
2.	downwinders	2.	lack of education
3.	mine/smeleter	3.	cement plant
4.	exposure to the sun	4.	sexual intercourse
5.	tobacco use	5.	soda pop
6.	cement plant	6.	alcohol use
7.	diet	7.	tobacco use
8.	lack of education	8.	chemicals
9.	heredity	9.	age
10.	age	10.	lack of breastfeeding
11.	alcohol use	11.	downwinders
12.	lack of YA lifestyle	12.	lack of drinking a lot of water
13.	soda pop	13.	lack of YA lifestyle
14.	lack of breastfeeding	14.	exposure to the sun
15.	sexual intercourse	15.	heredity
16.	lack of exercise	16.	lack of exercise
17.	lack of drinking a lot of water	17.	mine/smelter

In reviewing the two models of causes of cancer, it is interesting to note that the first ten items in the CHW's list are almost an inverted list of the KCs. The KCs top 10 items are all environmental causes in contrast to the CHW top ten items, which are primarily behavioral or lifestyle in nature.

Prevention Revisited

Following the review of the influence of the CHWs in the results of the consensus analysis regarding the ranking of the causes of cancer, a closer look at the potential influence on the previous ranking of the prevention of cancer was revisited.

Closer review of the prevention agreement matrix indicates that the CHWs are agreeing in 80% (.807 in the correlation matrix) on their rankings of prevention. There is only one other pair that is close at a correlation of .802. There are very few who reach that high of a level of agreement in the pairing.

These results indicate that the CHWs are agreeing with each other on their concepts of what is important in the prevention of cancer more than they are with almost anybody else in the sample. This could be because of their shared training background in prevention education with an emphasis of lifestyle change.

When the CHWs were taken out of the sample and the analysis was run a second time, the first to second eigenvalues ratio was 2.938 or approaching consensus. Although this value does not meet the guideline

of the 3:1 ratio, it may still be an indication that the inclusion of the CHWs is affecting the results, and they are not agreeing with the community as a whole.

It may be that the community does not have as strong agreement on the importance of prevention because they may not believe it is preventable. During the ethnographic interviews, when participants were asked if cancer could be prevented, there were many (55 per cent) who did not think it could be prevented, and believed that it “just happens”:

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.

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

There were an equal number of individuals who, although they were not aware of any way to prevent cancer, stated their concern that more education was needed for community members regarding early detection and treatment:

One of the most prominent concerns stated during the interviews by participants was regarding cancer causation related to potential environmental exposures. The three most commonly identified sources were: 1) the cement plant, 2) the Phelps Dodge copper mine, and 3) the impact of nuclear testing that took place in the 1950's in Nevada and the “downwind” effects to residents of the Verde Valley.

If they believe that environmental factors are the most important contributor to the cause of cancer in the community, they may also believe it is unavoidable and cannot be prevented. This may provide additional support that the environmental concerns of the community need to be addressed by providing information about the importance of regular screenings, as well as the need for enhancing a stronger prevention message about lifestyle changes that can prevent cancer.

Treatment

The cultural consensus analysis completed on the treatment rankings indicated no agreement. The first to second eigenvalues ratio was 1.839. When the sample was sorted by gender there was still no agreement found among women or among men.

When the CHRs were taken out of the sample, there was no increase in consensus. Because the sample size is small ($n=16$), it was not advisable to divide the sample into any smaller groups, as it could result in disproportionate group sizes with very small numbers that would influence the results. Overall, there was no agreement on the importance in the types of treatment for cancer among the KCs.

Although the KCs identified specific treatment modalities, there was no agreement on their importance. This may potentially have resulted from the indication provided during the interviews, that although they identified the different treatments, they stated they didn't actually know what each did in treating or alleviating the progression of cancer and many

actually stated that they caused the individual receiving the treatment to become even more sick and identified the treatment as “poison.” Within this context, it is possible this resulted in the lack of agreement on the importance of treatment.

Phase 2B: Pile Sorts – Organization of the Cultural Model

During a second interview, each individual was presented with three stacks of index cards containing the shared identified themes from the first ethnographic interview. This task was completed with the same set of three stacks of cards utilized for the ranking task, with themes specific to the same categories of: 1) prevention of cancer, 2) cause of cancer, and 3) treatment of cancer. The KCs were asked to complete a basic type of pile sort or “single sort” (Romney et al. 1979) for each stack. Each participant was asked to sort the index cards, with the identified themes on each card. They were asked to sort the cards into piles that they felt were more similar to one another. They could make as many or as few piles as they wished.

Pile sorts are tabulated and interpreted by measures of similarity, that is, each time a participant puts two items together in a group, it is counted as an indication that the respondent believes those two items are similar (Borgatti 1999). Pile sorts are used to obtain the structure of the domain. The more individuals that put any two items together, the stronger the interpretation that they are using the same cultural model.

The pile sort data was analyzed using UCInet (Borgatti, Everett, and Freeman 2002). UCInet created a similarity matrix for each individual and then compared the aggregate agreement across individuals. The results indicate if there is consensus or agreement about the way people are organizing or grouping the items.

If there is consensus, then the results can be aggregated. The results were then analyzed using cluster analysis and multidimensional scaling (MDS). Cluster analysis allows seeing how individuals grouped items together. The MDS allows for reduction of the averaged matrices into two-dimensional graphs of the distances between items. The closer the items appear together or are clustered together, the closer they are in meaning, as identified by the KCs. The MDS provide a visual representation of the relationship of the items based how the participants organized or grouped the items.

The measure of the goodness-of-fit of a given dimensional solution in MDS is referred to as “stress.” In interpreting stress values, in general, a high stress indicates a poor fit. In other words, the “mapped” MDS solution probably poorly represents the relationships calculated in the original similarity matrix. A stress value close to zero generally indicates an excellent fit. A normal threshold for stress is 1.2 – 1.4. If it gets above 1.4, there is concern that it may not be providing an accurate representation. The stress level for the pile sorts was .079, indicating that the representations are capturing the results accurately. Current research

suggests that much higher stress levels are acceptable than previously noted. According to the work of Sturrock and Rocha (2000), an MDS analysis that contains as many as 32 objects in two-dimensions can have a stress value as high as 0.33.

Following the rankings, the KCs (n=16) were asked to participate in an unconstrained pile sort. Participants were able to make as few or as many piles as they wished. They were asked to group items according to what they believed were similar piles, without reference to any specific criteria. They used the same categories and index cards used for the ranking task: 1) prevention (n=14), 2) cause (n=17), and 3) treatment (n=12). After completing the pile sort for each category, they were then asked what label or title they would give to each of the piles they had sorted.

Prevention

The analysis of the pile sorts specific to the prevention of cancer indicated that there was consensus. The first factor loading was 4.716, and the ratio of the first to second eigenvalue was 8.111, showing very strong agreement across the participants of the identified groups and the items in those groups.

The items were organized in three groups, containing a total of 14 items previously identified in the qualitative interviews, and shown in Table 5 below. The table also provides examples of the labels given by the

participants when they were asked to provide names for the piles they sorted.

The MDS results was constructed in UCInet and the cluster analysis was added onto this to provide the visual representation of the groupings are provided below in Figure 11.

Table 5

Results of Prevention Pile Sort

CATEGORY	GROUP	LABEL	ITEMS
PREVENTION (n=14)	1	"environmental factors" "chemical part" "may cause cancer" "modern effects/detriments to health"	avoiding soda pop avoiding alcohol use avoiding tobacco use avoiding exposure to chemicals avoiding exposure to the sun
	2	"healthy lifestyle" "prevention" "changes to prevent cancer"	exercise breastfeeding drink a lot of water diet education Yavapai-Apache lifestyle heredity age
	3	"prevention" "dangers" "nonsense" "sexual intercourse"	sexual intercourse

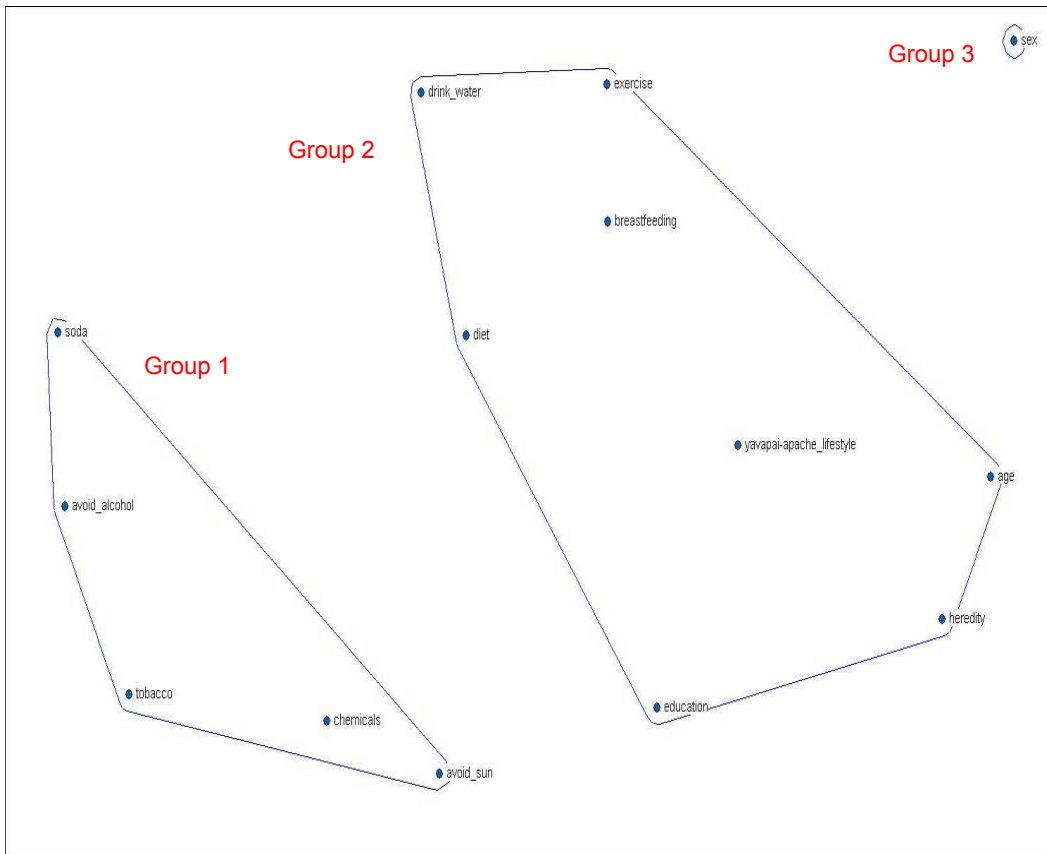


Figure 11

Prevention MDS Analysis

Utilizing the labels provided by the participants, the piles were sorted into: Group 1 – environmental factors; Group 2 – healthy lifestyle; and Group 3 – sexual intercourse.

The results indicate that although there is agreement on how the items are organized, these may not be very clear groupings. As illustrated in the MDS, the items in the healthy lifestyle or behavioral group are fairly

spread out and not tightly clustered. In contrast, the items in the environmental group are organized in a closer cluster.

The group identified as sexual intercourse is completely isolated and separate from the other groups. In order to get a better understanding of why this may have occurred, the ethnographic interviews and notes from the pile sorting exercise were reviewed. The one individual who initially identified this item when discussing prevention used it in the context of discussing the prevention of cervical cancer through the use of the human papillomavirus (also called HPV) vaccination among young women. HPV is the most common sexually transmitted infection.

However, as evident in the location of the item/group, as well as one of the identified labels (“nonsense”), it is probably more the case that the participants didn’t make the association of prevention of cancer, specifically cervical cancer, with the term sexual intercourse and the HPV vaccine.

In review of the outcome of results and responses among the participants, it may have been more appropriate to exclude this item in the prevention pile sort, as there seemed to be confusion or disregard for this term in association with the prevention of cancer, other than by one individual.

Cause

The analysis of the pile sorts completed by the KCs indicated that there was consensus. The first factor loading was 6.185, and the ratio of

the first to second eigenvalue was 7.886, indicating a very strong correlation or agreement across the participants.

The results indicated agreement in the creation of three groups of causes of cancer from the 17 items previously identified, and shown in Table 6. The table also provides examples of the labels provided by the participants for the identified groups.

Table 6
Results of Causes of Cancer Pile Sort

CATEGORY	GROUP	LABEL	ITEMS
CAUSE (n=17)	1	"chemicals" "main culprits" "things outside" "environmental causes" "main causes of cancer" "cancer causing/ingest outside"	downwinders mine/smelter cement plant chemicals exposure to the sun
	2	"cause by yourself" "lifestyle choices" "ways that cause" "can cause cancer" "warnings for cancer" "lack of education" "least cause of cancer"	tobacco use alcohol use soda pop diet lack of education lack of exercise lack of breastfeeding lack of drinking a lot of water sexual intercourse
	3	"Yavapai-Apache lifestyle"	age heredity lack of Yavapai-Apache lifestyle

The MDS results for the causes of cancer are also provided in Figure 12.

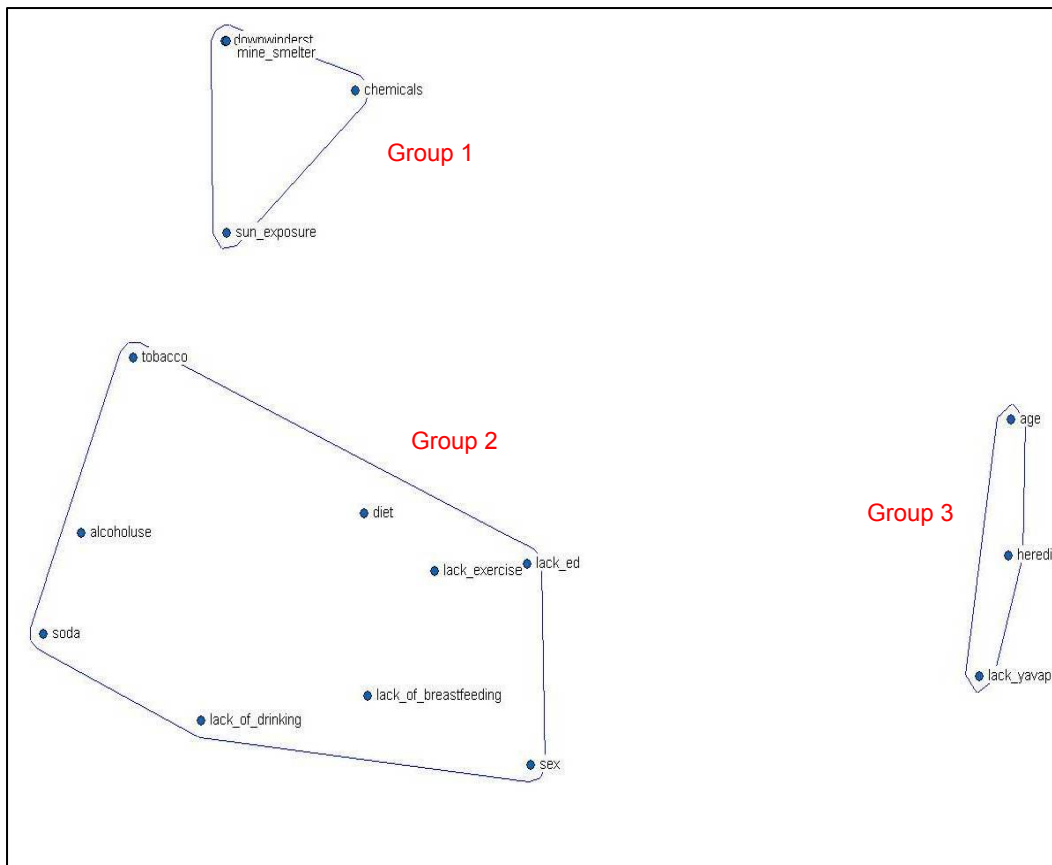


Figure 12

Cause MDS Analysis

The MDS findings indicate that the KCs have organized the causes into three groups. Based on the labels from the participants, it becomes apparent that the piles were sorted into: Group 1 – environmental; Group 2 – lifestyle choices; and Group 3 – Yavapai-Apache lifestyle.

The items in Group 1 are consistent from the analysis of the ethnographic interviews and the prominent concerns expressed by community members of environmental causes of cancer. These were identified as exposure to toxic waste potentially related to: 1) the cement

plant; 2) the former Phelps Dodge copper mine and smelter; and 3) the impact of nuclear testing that took place in the 1950's in Nevada and the "downwind" effects to residents of the Verde Valley.

The items in Group 2 were also identified in the interviews as causes of cancer that were primarily attributed to lifestyle choices and changes. These included tobacco use, as well as current diet choices and lack of exercise. Many had also expressed what they felt was a lack of education as contributing to the community's ability to understand and apply knowledge of cancer prevention education.

In reviewing the MDS results for Group 3 and to get a clearer understanding of why participants may have included these items (age, heredity, and Yavapai-Apache lifestyle), the ethnographic interviews were reviewed, as well as notes taken during the pile sort process. Those individuals who grouped these items together gave the explanation that they believed that one of the reasons there is more cancer in the community is that living a traditional lifestyle of more exercise (i.e. walking) and traditional foods is less common, although the cultural resource programs (both Yavapai and Apache practices) are making efforts of reintroducing several of these activities back into the community:

People back then they did a lot of their planting. They planted their own food and they lived off of their food. During the summer time, they would plant-- my dad was like a farmer, he planted . . . down here on Little Verde on the reservation . . . he had a big farm. . they did a lot of canning too. . We had peach trees . . . so we had that as like a dessert during the winter time. . . then there are certain times that they would go out besides farming they would get the acorn

and the piñons and walnuts. My dad used to go get us walnuts, pick walnuts and dry them out on a canvas because they were green and dry them out. . . And we used to eat walnuts and deer meat. We had a lot of deer meat. He'd go hunting every year so that was our meat part. . . we'd have meat every once in a while. But back then . . . the food part, I mean the lifestyle and the food. When you look at those stuff compared to now, like my children didn't really have much of that . . . And the other one was . . . They had the red berry juice. . . They picked it out here . . . the red berry . . . its sour. . . But you grind them, you make like they call it a Kool-aid, the Indian Kool-aid. . . But that was the drink they gave us. But talking about the lifestyle, the food, it's what you were brought up with and what you've had.

They felt it was a healthier lifestyle than modern diets (i.e. junk food) and lack of exercise they perceived as currently more common in the community.

Post-Hoc ANOVA Test: Ranking and Pile Sort on Causes of Cancer

The results of the pile sort and ranking of the causes of cancer both indicated there was consensus among the KCs with regard to the importance and categorization of the cultural model.

A simple Analysis of Variance (ANOVA) was run to see if one of the groups identified in the pile sort had a higher ranking of importance than the others. The ANOVA post hoc test would allow a comparison of all three identified groups together: Group 1 – environmental; Group 2 – lifestyle choices; and Group 3 – Yavapai-Apache lifestyle. The group number was the independent variable and the ranking was the dependent variable.

There was a very significant difference between the ranking values of Group 1, with p value = .18 (using model MSE of 6.873 with 14 df). The

lower ranking of group1 compared to Groups 2 and 3, respectively indicates that the environmental group (Group 1) is considered most important as a cause of cancer as ranked by the KCs, than the two other groups. There was no difference in the rankings between Group 2 (lifestyle choices) and Group 3 (Yavapai-Apache lifestyle).

The lack of difference in the rankings of importance of lifestyle choices and Yavapai-Apache lifestyle as causes of cancer reinforces the earlier findings in the ethnographic interviews with regard to the strong beliefs and emphasis on environmental factors as primary causes of cancer. Additionally, this is also reinforced with the resulting strong agreement or consensus found among the KCs in the ranking importance of environmental causes in the cultural model (i.e. chemicals, downwinders, mine/smelter).

Treatment

The analysis of the treatment pile sorts also indicated that there was consensus. The ratio of the first to second eigenvalue was 6.245, indicating a very high agreement.

The results indicated agreement in the organization of three groups of treatment for cancer from the 12 items, shown in Table 7. Examples of the labels by the participants for the identified groups are also indicated.

The MDS treatment results are also shown below in Figure13. It is clear that there is very good agreement on a very core set of items

organized in: Group 1 – spiritual/traditional ways; Group 2 – medical treatments; and Group 3 – last stage/days treatment.

As evident in the MDS representation, the groups are distinct but also very isolated and separate from each other. The hospice group is very separate, and most likely indicates the perception that it is a very different type of care or treatment unrelated to the other groups.

Table 7

Results of Treatment Pile Sort

CATEGORY	GROUP	LABEL	ITEMS
TREATMENT (n=12)	1	"Indian way" "must have" "spiritual beliefs" "spiritual/traditional road" "spiritual relief"	spiritual belief prayer attitude traditional practitioner traditional ceremonies herbs/plants
	2	"science road" "white man's way" "vital part" "medical" "cancer treatment"	checkups surgery medication radiation chemotherapy
	3	"last stages for family" "final stop" "last days"	hospice

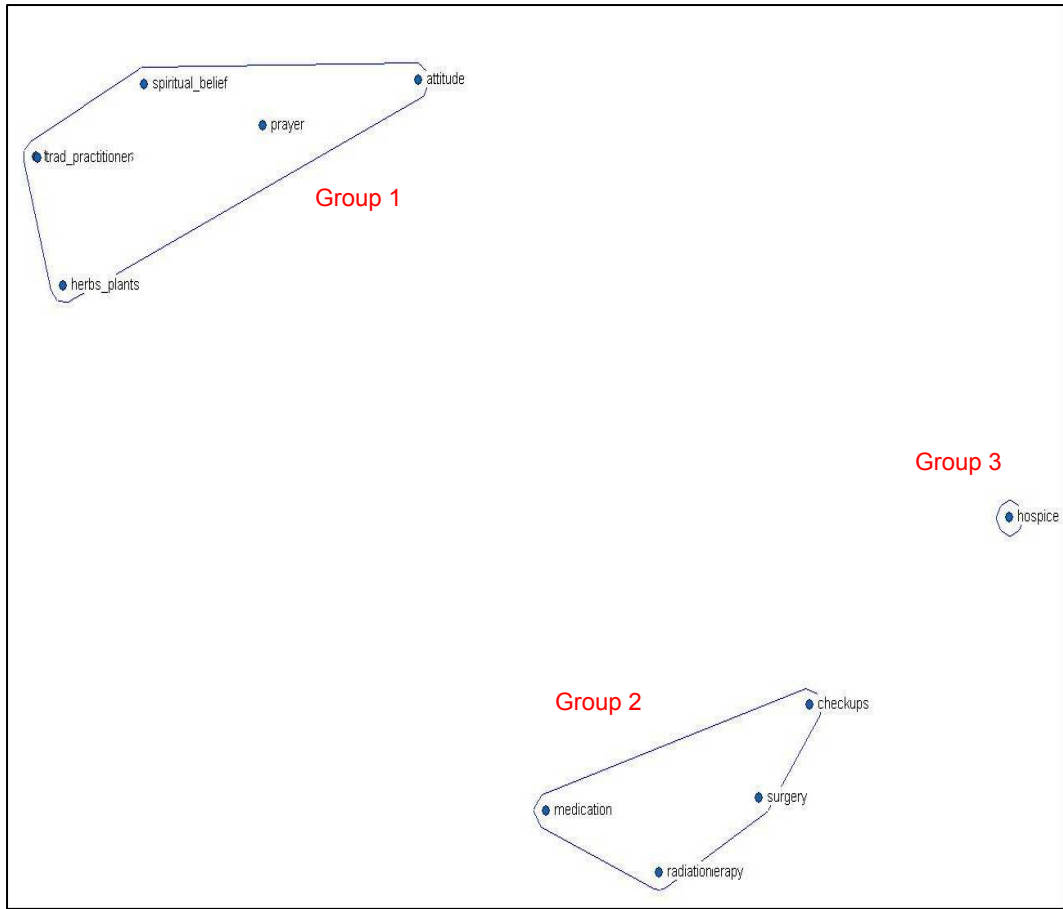


Figure 13

Treatment MDS Analysis

Phase 3: Community Survey - the Shared Cultural Model

The purpose of the community survey was to determine to what extent the ethnographic findings were shared within a larger community sample (n=74). The survey was developed from the ethnographic findings of the consultant interviews.

The survey questions needed to be reasonable indicators of the beliefs regarding cancer. The goal was to develop 20 or more questions/items, at the same level of difficulty. The items were reasonable indicators of the shared beliefs and balanced in terms of their positive and negative aspects. The questions had enough variation, so that there would be variation in the responses (Weller, 2007).

The final questionnaire also included inquiries about demographic characteristics and medical care access as well as knowledge, attitudes and practices related to cancer (i.e. preventive screening). (Appendix I)

A cultural consensus analysis (Weller & Romney, 1988; Romney et al., 1986, 1988; Weller, 2007) was used to determine if a shared set of cultural knowledge and beliefs was present in the Yavapai-Apache community then provide an estimation of that information. If it was determined that there was consensus, the results would provide estimates of the culturally correct answers and estimates of individual differences in the accuracy of the reported information as provided by the survey (Weller, 2007). Consensus analysis provides a means to evaluate the agreement among participants and to optimally aggregate their responses.

Given a series of questions on a single domain, each individual's "cultural competency" regarding the set of questions is estimated and then, the competency scores are used to "weight" the responses and obtain a Bayesian confidence level for each answer.

In addition to the sub-domains of the characteristics of cancer utilized in the rankings and pile sorts (i.e. prevention, cause, and treatment), descriptive content was also included specific to: descriptions of cancer, remission/cure and living with cancer, as noted in Table 8. There were a total of 60 questions used to determine cultural consensus.

Table 8

Community Survey Content

Sub-domain	n
Description	8
Risk/Cause	10
Prevention	7
Treatment	8
Remission/Cure	7
Living with Ca	<u>20</u>
TOTAL	60

The community survey allowed for collecting additional information and determining if there was agreement in these additional areas that had not been included in the pile sorts or rankings.

Additionally, the community survey allowed the examination of the knowledge and beliefs about cancer in a larger segment of the community and to be able to determine the extent to which the ethnographic findings were represented in the larger population.

Demographics

General demographic information was provided (Appendix M), as well as information regarding: 1) access to resource information about cancer, 2) screening information, 3) cultural activities and language use, 4) religious and spiritual background, 5) medical access, and 6) financial resources for medical care.

General Characteristics of Participants

Although all the participants were enrolled members of the Yavapai-Apache Nation, each tribal member may culturally identify themselves as either Yavapai, Apache, from both tribes, or from other tribal communities (i.e. Hopi, Navajo). There were 23 other tribal affiliations identified in addition to Yavapai and Apache.

The majority of participants (78%) indicated that they resided and/or worked in the communities of Camp Verde, Middle Verde, Clarkdale, or Rimrock. The remaining individuals live in the Verde Valley area. Over 36% have lived or worked more than 20 years or longer in the community. The majority of the participants felt that it was very important (85%) to maintain their tribal identity and stated they participated (85%) in cultural activities in the community. They identified some of these activities as: Sunrise dances, sweat lodge, basket weaving, pow wows, traditional blessings, preparing traditional foods, the Gathering of the Pais celebration, hunting, and ceremonies.

With regard to language, there was an equal number of participants (38%) who identified Yavapai or Apache as their tribal language, while the remainder identified both Yavapai and Apache (24%). Those who stated they spoke Yavapai (37%) or Apache (27%) indicated that they have varying levels of ability in speaking their tribal language (i.e. very well – little), and the remaining stated they either did not speak their tribal language but had an understanding (Yavapai-14%; Apache-18%) or did not speak or understand their tribal language (Yavapai-50%; Apache 56%).

Among the participants, the majority (42%) self-identified as Protestant, Catholic (8%), Latter Day Saints (Mormon) (8%), while others identified as practicing traditional tribal beliefs (21%) or are affiliated with the Native American Church (5%). Of those who identified an affiliation with a religious or spiritual practice, 78% indicated they were actively involved at varied levels (i.e. very involved, somewhat involved).

There was a large representation of participants who had never married (41%), were married (31%) or divorced/separated (20%). Many had completed high school (77%) and had continued their education (25%) to complete college degrees (i.e. AA, Bachelors, graduate). Additionally, a majority (64%) were employed and had an annual income of <\$30,000 (49%), with an average of 4 members per household.

Sources of Information

When asked if they used the internet to find out information about cancer, 64% stated they did not use it as a resource. However, 59% did say that their doctor provided them with needed information. This could be reflective of the average age (45) of the sample, or limited computer use in the community.

The majority (88%) did not think that there was not enough educational information about cancer provided in the community, and felt that the tribal newspaper would be one way to provide additional education and resource information (96%).

There are a couple of independent groups in the community who promote cancer awareness by sponsoring fundraising events and activities including walks, marathons, and basketball games. The participants (85%) indicated that these activities had made them more aware about the importance of the prevention of cancer. The majority (82%) indicated that they would be willing to attend more community events and presentations to receive additional information about cancer.

Screening

Over half of the participants (68%) have heard about medical tests that can detect cancer, however, only 32% have actually completed a cancer screening at a clinic or with their provider. This may be reflective of the age of the population and the current screening guidelines.

Over half (53%) of the women in the sample did indicate that they had a mammogram, but a minority (28%) stated they completed monthly breast self-exams. Although there has currently been controversy over the age guidelines of when women should begin screening mammograms, the National Cancer Institute (NCI) recommends that women age 40 or older should have screening completed every 1 to 2 years. This would indicate that the women represented in the sample (average age of 42), have a good awareness of the need for mammograms, but these rates could be improved with additional education and outreach.

A small sample of the men (29%) in the sample indicated they had been screened for prostate cancer, but this may also be reflective of their age (average 44). Current guidelines for screening tests recommend starting at age 50 for men at average risk for prostate cancer.

There were similar results when the participants were asked if they had ever been screened for colon cancer. There were a small number (22%), who stated they had completed screening. Men and women who are at average risk of colorectal cancer should begin screening tests at age 50.

Medical Care Access

When asked where they go the most often to see a doctor, 60% indicated the Yavapai-Apache Medical Center, while 28% receive care from a local private provider in the towns of Cottonwood or Sedona. Only 13% indicated they receive their care at the Indian Health Service,

Phoenix Indian Medical Center, located approximately 90 miles away or about a two hour drive into central Phoenix.

Living with Cancer

Similar to the experience indicated by the KCs, a majority (75%) of the survey participants indicated that they either knew someone or a member of their family (44%) had been diagnosed with cancer. Many were more aware of breast cancer diagnoses (34%) in the community.

Their knowledge of a person's ability to survive a cancer diagnosis was also similar to that of the KCs, in that the people they knew who had been diagnosed with cancer lived less than 5 years (22%) after diagnosis. Tragically, 18% knew individuals who survived less than one year after their cancer diagnosis. This information is reflective and a reinforcement of the community's perception that cancer cannot be prevented or survived. It also may be indicative of the lack of early screening. This is based on observing people being diagnosed with a late stage cancer diagnosis and dying in a shortened amount time.

Survey Results

The cultural consensus analysis was completed on a sample of 44, taken from the total sample of 74. There were 22 men in the complete sample who were case matched with 22 women of similar age. This approach enabled control for one variable.

The survey consisted of "yes" or "no" questions, so calculating agreement was straightforward. UCINET was used to calculate

agreement based on matching, adjusted for 50% guessing and then a PCA factor analysis was completed to determine consensus.

The results indicated that the first eigen value for the participants was positive and high. There was very good agreement among the sample of 44. The first to second eigenvalue was $17.506/3.958 = 4.42$.

The sample was sorted by gender to see if there were any differences in agreement. The results were similar to the total sample. The men had all positive and fairly high first factor loadings, with a first to second ratio of $8.508/2.181 = 3.90$. The results from the sample of women was a first to second ratio of $9.349/2.336 = 4.00$. So sorting the sample showed no significant difference in the resulting consensus in both groups.

The resulting consensus or agreement in the samples of men and women, as well as within the total sample indicated a single shared set of beliefs about cancer exists within each. Because there is consensus, there is justification in aggregating the responses to the questions into a modal response (based on the average across the respondents). This resulted in a shared cultural answer key of the survey questions, shown below in Table 9.

The overall results can be reviewed looking at the raw group averages, as well as the “no” answers. In the “description of cancer”, two items that don’t reflect strong agreement values is the question of whether cancer is common among American Indians and Alaska Natives (AI/AN)

(51%) and whether cancer is preventable (68%). This will be discussed in further detail in the next chapter.

Within the “risk/cause” questions, there wasn’t a strong indication (60%) of knowledge that elders are at greater risk for cancer due to their age, or the potential cancer risk related to alcohol use (60%).

The overall strength of the responses to the questions about “prevention” would seem to indicate an understanding of the value of living a healthy lifestyle in the prevention of cancer. There is also an agreement in the value of medical check-ups (84%) and screenings (97%) in early detection and prevention.

Within the sub-domain of “treatment”, there are interesting results reflecting differing knowledge and beliefs about the types of treatment. Overall there is strong agreement in the answers related to biomedical treatment (radiation, chemotherapy, surgery). However, there is less agreement about treatment of cancer with herbs/plants (57%), traditional ceremonies (60%), and by traditional practitioners (51%). This will be discussed in further detail in the next chapter.

In “remission/cure”, there is agreement that although cancer may go into remission or stop spreading (66%), it doesn’t mean the cancer has gone away (82%) and that there is likelihood that it will come back (91%). Some participants do believe that there is the potential for a cure through prayer (57%) and miracles (66%).

Table 9

Knowledge and Beliefs about Cancer

Category	Item	Resp	Group Average
DESCRIPTION			
	death or dying	Y	70%
	deadly disease	Y	88%
	something to be feared	Y	82%
	contagious	N	96%
	curable	Y	84%
	common among AI/AN	Y	51%
	preventable	Y	68%
	uncontrolled growth of cells	Y	86%
RISK/CAUSE			
	elders at greater risk	N	60%
	chemicals	Y	93%
	being a "downwinder"	Y	97%
	living near mine/smelter	Y	86%
	heredity	Y	70%
	alcohol use	N	60%
	types of foods	Y	64%
	smoking	Y	95%
	chew tobacco	Y	95%
	2nd hand smoke	Y	97%
PREVENTION			
	breastfeeding	N	67%
	cancer is preventable	Y	74%
	increase education/knowledge	Y	91%
	regular exercise	Y	58%
	nutritious diet	Y	79%
	tests can detect early	Y	97%
	regular medical check-ups	Y	84%
TREATMENT			
	treated with herbs/plants	Y	57%
	chemotherapy	Y	97%
	treated by traditional practitioner/medicine man	Y	51%
	treated by traditional ceremonies	N	60%
	radiation	Y	93%
	surgery	Y	91%
	chemotherapy	Y	95%
	loss of hair	Y	95%
	radiation causes fatigue	Y	93%

Table 9 (cont'd)

Knowledge and Beliefs about Cancer

Category	Item	Resp	Group Average
REMISSION/CURE			
	comes back after treatment	Y	91%
	goes away completely after treatment	N	58%
	can be cured	Y	68%
	prayer	Y	57%
	miracles	Y	66%
	stops spreading in body (remission)	Y	66%
	doesn't have cancer anymore (remission)	N	82%
LIVING WITH CANCER (COPING/SURVIVING)			
	positive attitude	Y	68%
	denial and coping	N	73%
	eat a healthy diet	Y	77%
	faith in God	Y	70%
	prayer	Y	70%
	read the Bible regularly	Y	60%
	spirituality	Y	70%
	family support	Y	84%
	practice traditional/cultural beliefs	Y	65%
	participate in traditional ceremonies	Y	62%
	treatment from traditional practitioner/medicine man	Y	53%

In “living with cancer,” participants agreed on the importance of a positive attitude (68%) and the negative effects that denial can have in coping with a diagnosis (73%). The role of faith in God (70%), prayer (70%), reading the Bible regularly (60%), spirituality (70%) and family support (84%) were all seen as important in living with a diagnosis of cancer. It is also interesting to note that there was a small increase in averages in the questions regarding the importance of the role of traditional/cultural aspects (beliefs, ceremonies, and treatment from a traditional practitioner/medicine man) in living with cancer in comparison to these same items when related to their importance in treatment. This may reflect the participants’ belief about the role of traditional/cultural practices as it relates to cancer as being potentially more effective in the role of helping a person cope with a diagnosis rather than in the treatment of cancer.

Summary

This chapter provided the results of the analysis of the three phases of the research study: 1) ethnographic interviews – identification of the themes or the content of the participants’ cultural model, 2A) ranking of the themes – determining the agreement of the importance of the content of the cultural model, 2B) pile sorts – determining agreement on the organization of the model, and 3) the community survey – identification of the shared model of cancer knowledge and beliefs in the greater community.

The rankings indicated there was no agreement or consensus in the importance of specific concepts of prevention or the importance of types of treatment. However, there was consensus about what were important causes of cancer. The items listed as the most important causes (i.e. chemicals, downwinders, mine/smelter) reflected similarity to the findings of the ethnographic interviews with a common focus of items related to environmental exposures.

The results of the pile sorts provided strong evidence of agreement among the participants on the organization of a cultural model of prevention, causes and treatment of cancer.

The consensus reached in both the pile sorts and ranking specific to causes of cancer provided an opportunity to run a post-hoc ANOVA indicating that the participants were in agreement that the most important cause of cancer in the community was related to environmental factors.

A possible explanation for consensus that was found across all three sub-domains (i.e. prevention, cause and treatment) in the pile sorts, compared to agreement found in only in the ranking of cause could be related to the difference in the nature of the two tasks. Participants may not have had as much difficulty in creating categories within the sub-domains, as compared to agreeing on the importance of different aspects of prevention and treatment. However, the agreement in ranking the importance of the causes of cancer specific to environmental exposures

reinforces a common cultural model found both in the qualitative and quantitative methods.

The results of the community survey provided evidence of overall strong agreement or consensus in the sub-domains of descriptions of cancer, risk/cause, prevention, treatment, remission/cure and living with cancer.

Further discussion about the results, applications limitations and potential impacts will be presented in the next chapter.

CHAPTER 7

DISCUSSION AND CONCLUSION

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 study was to utilize a cultural consensus method to identify the cultural knowledge and beliefs about cancer in a southwest American Indian community. The methods utilized to answer the research questions include the results from both qualitative and quantitative data.

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 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?

This final chapter provides an overview of the research findings; a discussion of the limitations of the study; the potential implications to policy, programmatic development, enhancement of existing services; and the importance of meaningful research partnerships with tribal communities in continuing future research in addressing health disparities.

Why was it done?

The cultural consensus method has not been utilized to date in identifying the collective cultural beliefs about cancer prevention, treatment or survivorship in a Native American community. Its use represents a methodological step forward in two areas.

First, the traditional ethnographic inferences used in identifying and defining cultural meaning as it relates to health can be tested more rigorously than in the past. A second significant contribution of this method is that it addresses the challenge of providing reliable results based on a small number of community informants, thereby avoiding the necessity of acquiring large sample sizes to objectively ensure the confidence of the responses provided. This is especially significant when working with smaller American Indian and Alaska Native (AI/AN) communities where the small sample size has led to questions concerning the reliability and validity of health-related research. As a result, it is often challenging for tribal communities to successfully submit research proposals and acquire funding to develop projects to address health disparities.

What are the cultural beliefs that may influence the response of a community to illness and disease? How can shared cultural knowledge regarding illness and disease be described and measured?

Anthropologists have long had an interest in studying and recording ways in which different cultures deal with, think about, and integrate disease into their wider systems of beliefs, values and behaviors. This interest is now receiving greater visibility with an increased awareness of and priority in understanding and addressing the impact of health disparities within Native American communities in the United States.

Community-Based Participatory Research (CBPR)

One of the most significant contributions to the successful implementation of this research study was the meaningful involvement and contribution of the Yavapai-Apache (YA) community throughout all aspects of the project.

Community-based participatory research (CBPR) principles were applied in the development and implementation of the research project, including, facilitating a collaborative and equitable partnership in all phases of research; building on the strengths and resources within the community; and disseminating findings and knowledge to all partners and involving them in the dissemination process.

Experienced and junior researchers, who are committed to actively engaging in a meaningful research partnership with communities, are

familiar with the potential benefits of utilizing a CBPR approach. However, a testing of that commitment will come early and from many sources.

Challenges and Successes

Conducting research in a small, rural community can pose challenges that initially may not have been considered. These could include: lack of anonymity to the participants because “everyone knows everyone”; possible unspoken rule of silence regarding other people’s health or health circumstances; limited resources (or infrastructure) with health staff wearing more than one hat that may challenge boundaries between personal and workplace roles becoming blurred. This is especially true when collecting information about a disease or illness that, based on cultural knowledge, many may consider as potentially compromising to their own health by simply participating. This can have a significant impact on the success of adequate data collection or may exclude a specific segment or demographic of the population.

However, by successfully implementing CBPR and engaging the community throughout the research process, some of these challenges can be addressed or avoided because of local knowledge and understanding of the community’s culture. Additionally, the community’s trust in other community members engaged in the research process and their advocacy about its importance and benefits of the research, as well as trust in the researcher, is invaluable to the successful implementation of the project research.

I had a long standing relationship with the community in a previous public health capacity, and it might be assumed that this would have contributed to an immediate entry in the development and implementation of the research study. I had actually assisted the tribe, per their request, in acquiring their specific SEER cancer data from the University of New Mexico over a two-year period, as well as assisted in advocating and facilitating the provision of allocated health and medical health services from the IHS. However, even with the established trust that had developed over that period of time, it didn't prepare me for the added research approvals that became necessary due to external circumstances beyond my control.

As mentioned in previous chapters, one of the most significant considerations in the implementation of the study were the additional approvals, independent of the University IRB approval, that were required before data could be collected. This was as a direct result of a pending lawsuit that had not reached its conclusion and settlement prior to the submission of the research project for approval from the Yavapai-Apache Nation and the Arizona State University's (ASU) IRB. The lawsuit had been filed in 2004 by the Havasupai Tribe of northern Arizona against ASU and its Board of Directors, as well as two professor/researchers from my academic department, charging the misuse of blood samples taken from tribal members (Shaffer, 2004). The research review and approval

process included: 1) the YA Tribal Council, 2) the University Advocate for American Indians, and 3) the ASU IRB.

The significance of these circumstances were not only from the perspective of a graduate student from the institution and department directly involved in the lawsuit, but from the community's perspective this case had directly impacted their "relatives", the Havasupai tribe.

Dr. Peterson Zah, former President of the Navajo Nation, served in the position of University Advocate/Special Advisor to the President, American Indian Initiatives since 1995. His primary focus and role has been on improving the university's relationship with tribes and on recruiting and retaining Indian students. Additionally, in response to the issues related to the Havasupai case, all research studies that involved American Indian communities were initially reviewed through his office, and if approved, were then sent to the ASU IRB for review and approval after meeting the required criteria.

In consideration of the required levels of research review, I had an initial meeting with Dr. Zah one year prior to the formal ASU IRB review. I had already been working collaboratively with the YA Community Advisory Committee (CAC) in the development of the research proposal and applying CBPR principles throughout the process. The purpose of the initial meeting was to request clarification of the criteria needed to enhance a positive IRB review.

Upon provision of the project abstract and summary, including the role of the CAC throughout the research project, the University Advocate indicated that the application of CBPR principles in working with the YA Nation was the appropriate collaborative model in addressing the IRB policy when conducting research with American Indian communities.

Following the final review, amendments and approval of the proposed research study by the YA CAC, the proposal was presented before the Yavapai-Apache Tribal Council for discussion and review. The YA Tribal Council voted to support the research study, and approved the request of a tribal resolution in support of the study to be conducted in the community (Appendix A). However, the Tribal Council also indicated that an additional requirement needed to be met before any research could be initiated. They required that a written statement be provided from ASU stating that the YA Nation would have the opportunity to provide final review of the information, results, findings and dissemination of the information presented resulting from the research and that the information shall remain the proprietary and confidential information of the YA Nation until the Nation determines otherwise.

The research proposal with the supporting YA tribal resolution was provided to the Office of the University Advocate/Special Advisor to the President, American Indian Initiatives and the ASU IRB for review and approval. The research study was considered exempt after review by the

IRB pursuant to Federal regulations, 45 CFR Part 46.101(b) (2) (see Appendix B).

A letter addressing the additional requirement stated by the YA Tribal Council was provided from the ASU Office of Research Integrity and Assurance from the University Advocate/Special Advisor to the President, American Indian Initiatives (Appendix C) to the Yavapai-Apache Nation. Upon receipt of the letter, the YA Nation approved the initiation of the research study activities.

When the study was completed, the final results and dissertation were reviewed initially by the YA CAC, then to the Tribal Chairman, and the full membership of the tribal council. A tribal resolution was requested and approved (see Appendix O) in support of the dissertation submission to the ASU Library (and Library supported search engines) electronically through ProQuest/UMI Publishing.

I believe that the application of CBPR principles in partnership with the community from the initial development of the research questions with tribal health representatives (and eventually a community advisory board) was the contributing factor to the success in completing the research study. They were actively engaged and involved at every level of development of the proposal, the interview schedule, outreach to potential participants, review of the survey, the results, and the dissertation chapters. It was an honor and a privilege to participate in this rewarding and productive research partnership.

What could other researchers learn from this experience? Or how could this contribute to establishing trust in productive research partnerships with Native American communities?

First, the commitment to a CBPR approach goes hand in hand with a willingness to invest the needed time to the process of meaningful engagement with the community as an equal partner in the earliest planning stages of the research. And as an equal partner, they are also committing to the additional time they are investing throughout the implementation of the study. The foundation of the research relationship is both the trust and commitment from both partners to jointly contribute to addressing the health concerns as identified by the community.

Second, the commitment to a CBPR approach in working with Native American communities should extend to revisiting IRB policies within academic institutions. It is unfortunate to have recently heard that two separate research/academic institutions would rather avoid research relationships with Native communities than confront what they may consider as a time consuming research approval process. Rather, what should take place is facilitation of policy that ensures that researchers have established working relationships “with” tribal communities as opposed to research “at” communities. This could be accomplished by insuring that proposed research must include evidence of an engaged research partnership by including accompanying tribal council resolutions approving the research, prior to IRB review. Additionally, researchers

should also be required to submit any draft publications for tribal council review and approval prior to submission to academic journals. A tribal resolution or acknowledgement from tribal communities would then need to be reviewed and approved by the IRB prior to publication submissions. This is currently a requirement by the Indian Health Service (IHS) IRB on all research conducted in IHS facilities in tribal communities.

Proactive steps by academic institutions in developing policies that ensure meaningful research partnerships with tribal communities would provide evidence of the commitment to ethical research principles that would facilitate productive outcomes that would benefit both, including needed research to address health disparities, as well as other issues for which research is needed for tribal purposes.

For many new, as well as established, investigators there is often a hesitancy and perhaps even a direct avoidance in attempting to develop research projects in Native American communities based on what many consider an over commitment of time for endless reviews and approvals. Specific to this study, however, this was not the case and the time for the review and approvals was probably an average of most other studies conducted in general communities. It is unfortunate if this is a bias for other investigators, as the benefit of the exchanged knowledge and experience gained in a genuine research partnership will not occur.

The challenges to conducting research with Native American communities are as a direct result of a long-standing and well-founded

distrust of research that has represented yet another means of oppression by the predominant culture. Even the best intentions of scientists may go awry in the interface between the sometimes immensely diverse worldviews of the scientific and the Native American communities. Using a community based participatory research (CBPR) approach to form academic community partnerships with Native American people may provide a means to rebuild trust in the research process.

As was evident in the experience of this research study, CBPR is the most appropriate approach in taking steps to changing the negative history of research encounters in Native American communities into a more productive and beneficial partnership in effectively addressing community health disparities as well as other issues of concern.

Answers to the research questions

The answers to the research questions were provided from the three phases of research that were undertaken: 1) ethnographic interviews – identifying themes or the content of the participants' cultural model, 2A) ranking of themes – understanding the relative importance of the content of the cultural model, 2B) pile sorts – the organization of items within specific domains, and 3) community survey – whether the model is shared in the greater community.

Knowledge and Beliefs about Cancer

The first research question was, “What are the community members' knowledge and beliefs about cancer?”

When asked what some of the first thoughts that may come to a person's mind when they hear the word cancer, the KCs responded that their first thoughts were about death or dying.

What may be some of the contributing factors as to why the interview participants voiced what may be seen as a fatalistic attitude about cancer? Throughout the interviews, many stories were described in such a way that would indicate that the cancer experience for many families and community members was one of late diagnosis. Several were diagnosed and died within six months to one year. Tragically, these circumstances are reflected in AI/AN communities throughout the U.S. as evidenced in survival rates that are lower than any population group in the U.S. (Boss, 1986; Department of Health and Human Services, 2009).

Part of the reason for the high mortality is that AI/ANs are more likely not to be diagnosed until the cancer is at an advanced stage (Mahoney & Michalek, 1991; Department of Health and Human Services, 2009). The reasons for these circumstances could be related to fear, lack of knowledge of what types of screening tests are available, how they are done, when is it appropriate for individuals to seek annual screening, and payment and transportation issues. During the interviews, a few individuals were familiar with mammography, colorectal and prostate screening tests, but also indicated that some of the tests were embarrassing to talk about and they did not know what was done during the screenings, what financial resources were available to pay for the

services, and where they could go for tests not provided at the tribal health clinic. These same issues have been attributed to poor cancer survival rates among Native women in other studies and were also attributed to fear of cancer which influenced a delay in seeking appropriate treatment, cultural beliefs, and underutilization of available treatment options (Braun, Look, & Sark, 1995; Department of Health and Human Services, 2000; Horner, 1990)

The feelings of fear that were expressed during the interviews were also related to the unknown nature of cancer as a new and unfamiliar disease to their family, community and culture. Many expressed that they lacked the knowledge and information about what it was or what it was doing to the body, or if it could be treated or stopped. Several actually described their understanding about the process of what cancer is doing to the body as something that “eats you up” and can’t be controlled.

If the occurrence of cancer is perceived as incurable or affects people at random, as expressed by the KCs, this will only compound the issues of fear and a fatalistic attitude and prevent people from seeking appropriate screening or medical care at an earlier stage when treatment may have a more effective outcome.

Lack of access to comprehensive cancer prevention information, in combination with a lack of access to appropriate screening services or financial resources to pay for preventive screening will likely continue to contribute to late stage diagnosis in the community unless this is

addressed. It is important to address these issues by providing culturally appropriate, accessible and basic information about cancer, including the importance of early screening, availability of resources for payment of medical services (specific to early/annual screening tests). Many participants indicated that they would like more information about cancer and would be interested in accessing these information/educational services if they were made available in the community.

Agreement or Consensus in Beliefs about Cancer Prevention

The second research question was, “Do they believe it (cancer) can be prevented?”

What might be some reasons for the lack of agreement on the importance of specific ways to prevent cancer by the community? This could be as a result that over half of the participants expressed a belief that cancer was not preventable and something that “just happens.” If a person believes that cancer happens at random and anyone can be at risk, including healthy adults and children, than the importance of specific concepts of prevention may be lacking or not exist, and may explain the lack of agreement among participants.

The KCs did agree in organizing what may be items of prevention in categories they identified as environmental and behavioral issues or lifestyle choices. How is this related to the lack of agreement regarding the importance of specific ways to prevent cancer?

With regard to the promotion of lifestyle choices or behavioral issues in the prevention of cancer, it continues to be a challenge in public health promotion and education that there is not a singular or combination of “healthy lifestyle choices” that have proven to successfully prevent cancer. The exception to this argument may be smoking cessation. However, in general there is the “likelihood” and “probability,” but to date there hasn’t been definitive research regarding specific successful behavioral/lifestyle approaches proven to prevent cancer. The lack of a consistent message to the general population about definitive ways to prevent cancer based on lifestyle change makes it a challenge to develop effective prevention education messages. It may be more appropriate to frame cancer prevention in terms of reduced risk as opposed to strictly prevention.

Additionally, there are multiple challenges in the promotion and subsequent application of living a healthy lifestyle and change of behavior in lowering the risk of cancer. Attaining healthy lifestyle changes can be problematic for individuals and communities where economic resources that would contribute to accomplishing this are often not readily available.

In many AI/AN communities, there may also be cultural perceptions and values associated with food that represent personal and familial expressions of affection and a means to foster and maintain kinship ties (i.e. served at funerals, community celebrations, as part of traditional

gatherings and ceremonies) that would make it inappropriate to refuse or avoid what may be considered “unhealthy,” outside the community.

An extreme example of this recently occurred when a nationally televised weight loss program came on location in the community within the past year. The well known host of the program came to work with a family that had been selected to participate in the televised program over several weeks. During the opening episode, the community held a welcoming event and prepared dinner to honor the host. One of the foods to be served was “fry bread”, which is served in a majority American Indian communities, and is considered traditional food, although was most likely first introduced when rations, including flour and lard, were distributed by the military on American Indian reservations. After a blessing by an elder was offered, and the food began to be served, the television host/personal trainer walked over to the serving table, picked up the pan of fry bread that had been prepared for the meal, and emptied it into a trash can. The host made the pronouncement that they should no longer eat “fry bread,” that it was making them unhealthy and obese and it was not traditional food. The community members were initially shocked and then angry at what they believed to be shameful behavior and wasting of food, as well as an insult to the community’s hospitality in preparing the meal in her honor. Although the program’s focus was in reducing obesity and not specific to cancer prevention, it was perhaps one of the most

culturally inappropriate and damaging approaches in promoting lifestyle/behavior change in the community.

Developing an effective cancer prevention regarding lifestyle/diet change may face the residual negative effects of this incident that occurred in the community. Any effort to promote a healthy diet and lifestyle change may only be effective if there is a specific risk reduction message that incorporates cultural considerations and the role of food in the community.

It may be that although there is agreement that there is a category of environmental issues of prevention, the community may not believe that these same issues can be prevented (i.e. chemicals, exposure to the sun). In other words, these may be perceived as external or outside of individual control and may have been reflected in the statements of cancer “just happens”.

The results appear to be an indication that the community has not received a strong or cohesive prevention education message about ways to prevent cancer and may build a case for the need to develop or enhance the public health information in cancer prevention currently being provided.

Agreement or Consensus in Beliefs about the Causes of Cancer

The third research question was, “Is there cultural consensus or agreement in the community regarding the cause(s) of cancer?”

The strong agreement among the KCs that resulted when the CHRs were separated from the original sample provides an interesting point of discussion. Especially interesting is that the cultural model of causation among the KCs that focused on the environmental issues related to their lived experience of chemical exposure, including the related evidence of “downwinders” and their families receiving compensation from the federal government based on the provision of evidence of the timeframe of their residence in the community and documentation of diagnosis of qualifying cancer sites. Additionally, the existing tail pilings and leach ponds related to the mine/smelter and particulate air pollutants from the cement plant are contributing factors to the identified cultural model of environmental causation.

However, the CHRs identified almost an inverse identification of causes of cancer in their response and emphasized items that were indicative of lifestyle/behavioral change based causes or items related to individual responsibility. The follow-up interviews with the CHRs and review of the training modules provided by the IHS, indicate that a standard public health prevention approach is applied in the CHR curriculum and training, with a focus on individual responsibility and behavioral choices as contributing causative factors.

The CHR program provides a critical role in its contribution to improving the health of AI/AN communities. However, a challenge to the IHS may be to provide the needed technical support and resources for

CHRs to specifically tailor their services and messages to more effectively respond to the unique needs and cultures of the communities they serve. In this case, because of the community's experience and their perception that environmental causes are contributing to the cases of cancer in the community, providing a public health prevention education and causation model of cancer based on individual responsibility may not be effective unless the environmental concerns that have been identified are addressed.

It may be more effective to provide assistance in methods of addressing broader environmental justice issues. The basis of applying environmental justice in AI/AN communities is focused on tribal sovereignty issues that are a means on preserving the cultural and physical well-being of the community. Additionally, the principles of self-determination as it relates to the community developing broader policy to protect its members from potential environmental health hazards would be the mechanism to address these concerns related to cancer.

It may be an unreasonable expectation and out of the scope of the CHR program to respond to these larger environmental justice issues, but providing resources and appropriate referral environmental organizational information to assist the tribal government to begin assessing any potential environmental hazards that may potentially be increasing cancer rates in the community will be essential. This is an area where the

researcher may be of assistance in locating information and resources as well as an area where tribal government may need to become proactive.

The other two groups identified within the cultural model of causation were lifestyle choices and the Yavapai-Apache lifestyle. Within the category of lifestyle choices participants throughout the interviews and in the resulting rankings and pile sorts indicated that these were “caused by yourself,” or by individual decision-making, as opposed to the environmental causes they ranked as most important. It is interesting to note, that within the ranking of importance within the cultural model, “lack of education” ranks higher than the other items of “lifestyle choices”. This item was repeated often by a majority of the participants during the interviews when expressing their concern that they believed there wasn’t enough information being provided in the community about the causes of cancer, as well as in ways to prevent, treat and live with cancer.

This provides a tremendous opportunity to develop and/or enhance the current availability of comprehensive cancer information about different kinds of cancer, treatment, and prevention strategies, as it is an expressed need that has been identified by the community. An appropriate approach would to solicit the participation of the other tribal health and social services programs in determining successful methods of engaging community members to participate in their program activities, as well as what are potential related health programs and/or activities that

could be appropriate in incorporating needed cancer information that has been identified by the participants of the study.

Another example of a similar approach that could be successful is in addressing the identified cause of the “lack of Yavapai-Apache lifestyle” (i.e. diet, exercise/activity). In reviewing the MDS results for the Yavapai-Apache lifestyle group, and to get a better understanding of why participants may have included these items (age, heredity, and Yavapai-Apache lifestyle), the ethnographic interviews were reviewed, as well as notes taken during the pile sort process. Those individuals who grouped these items together gave the explanation that they saw the lack of living the past cultural lifestyle of a healthy diet (i.e. fresh fruit, vegetables) and exercise, as possibly contributing to causing cancer. They felt it was a healthier lifestyle than modern diets (i.e. junk food) and included much more physical activity than what they perceived as a current inactive lifestyle in the community. Currently, the Yavapai-Apache Cultural Resource Center has a “Lifeways and Life Skills” program that provides special educational opportunities for both youth and adults in the community, and includes teaching ways of living off the land, gathering traditional foods and medicines, such as mesquite, saguaro fruit, acorns, red berries, agave and herbs. The program schedules seasonal community outings in demonstrating the gathering of traditional plants and foods, as well as the appropriate preparation of each. It may be appropriate to work with the managers of the programs to incorporate and

enhance a cancer risk reduction message, in addition to emphasizing the importance that the role of traditional lifeways may contributing to increasing the health of the community by reducing health disparities (i.e. cancer, diabetes).

Agreement or Consensus in Beliefs about the Treatment of Cancer

The fourth research question was, “Do they believe it (cancer) can be effectively treated or cured?”

Similar to the results regarding the prevention of cancer, there was no agreement among the interview participants about the importance of a specific treatment for cancer. This may be attributed to the participants statements that although they were familiar with different types of treatment (i.e. chemotherapy, radiation, and surgery), when asked to describe what these 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, and described the effects that often included fatigue and hair loss experienced by the person being treated. The lack of agreement on the importance of specific types of treatment may be due to the lack of information about the purpose of the different types of treatment, how they work, and how each may be successful in the treatment of cancer.

There was agreement in identifying three groups or types of treatment for cancer. These included: 1) spiritual/traditional ways, 2) medical treatments, and 3) last stage/days treatment.

Specific to “spiritual/traditional ways”, among interview participants there were very few that spoke of their knowledge of family or community members who utilized traditional providers or ceremonies as an option for treatment. However, two individuals did speak about the use of specific plants or herbs they knew had been used for treating cancer. Another person mentioned someone they knew who had incorporated the use of the sweat lodge for treatment after receiving a diagnosis of cancer. This was also reflected in the survey results in indicating that community members weren’t in strong agreement, or a slight majority, regarding the use of herbs/plants (57%), traditional ceremonies (60%), and by traditional practitioners (51%) in the treatment of cancer.

A possible explanation for the lack of agreement about the importance of the role of spiritual/traditional ways in the treatment of cancer may be due to the fact that cancer is perceived as a relatively new health problem in the community, and the use of traditional interventions may not be seen as an appropriate form of prevention or treatment.

Individuals from the interviews and community-wide survey stated that they thought cancer would go away permanently after a cancer diagnosis and treatment, and about half believed that it was possible that it could be cured. There was agreement among those who specifically

referred to “remission/cure,” that although cancer may go into remission or stop spreading/growing, it doesn’t mean the cancer has gone away and they believed there is the likelihood that it will come back.

As noted previously, a comprehensive cancer education program would need to include more specific information about the types of treatment and provide general information about the purpose of each and success rates. If the community is not aware that there are successful treatment outcomes, it could potentially contribute to individuals not seeking appropriate care. If they believe that cancer cannot be treated successfully, and it is perceived as only increasing the discomfort and pain already being experienced by the person diagnosed with cancer, these beliefs and attitudes may reinforce the outcomes of late diagnosis because of a delayed response in seeking appropriate screening, diagnostic services and treatment.

Beliefs about People Living with a Diagnosis of Cancer

The fifth and final research question was, “What do community members believe are reasons that a person continues to live even after they are told they have cancer?”

When asked how a person is able to continue to live with a diagnosis of cancer, those who were interviewed identified five different areas they felt had a direct impact on the quality of life of a cancer survivor, 1) a change in lifestyle, 2) ongoing treatment and medical care,

3) support from family and friends, 4) their attitude, and 5) the strength of their faith or spirituality.

When people spoke about a change of lifestyle and its influence on extending the life of individuals living with cancer, they referred to efforts to be active and eating a healthy diet.

Continuing or seeking ongoing treatment was also mentioned by several participants. One individual mentioned the experience of a family who sought and received an experimental treatment or clinical trial that was available at an oncology clinic.

Many of those interviewed, as well as a majority (84%) of those completing the survey, emphasized the importance of the support that cancer survivors needed from family and friends. 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.

These three areas would need to be included in the comprehensive cancer education program development efforts, and may be more appropriately provided by programs and staff at the tribal health clinic. There are currently existing educational modules provided by the American Cancer Society, the Wellness Community and the National Cancer Institute addressing the nutritional and activity needs of cancer survivors, but these may need to be adapted to meet the needs of the community in terms of clarity in explanations and terminology used. An

additional consideration may be the appropriateness for those who may be dual diagnosed with diabetes and cancer and the considerations needed for both. There are also many resources providing information about clinical trials, their availability, as well as financial resources that support patient access.

To encourage and support ongoing access to treatment and medical care for cancer patients in the community, it might be suggested that an assessment be conducted by the tribal medical clinic in partnership with the CHR Program to determine the current support services being provided and determine if there is need to enhance current services or if there are additional needs that need to be addressed in follow-up care and staff/provider education.

Specific to the need of cancer support group services, it might be necessary to determine if cancer survivors and their families are comfortable in participating in support groups provided in their community, or would prefer to attend groups currently being provided in Cottonwood (approximately 30 minutes away). There is often the challenge in rural or small communities, that it is considered a “risk” to attend such activities as they may lose their anonymity because community members may become aware of who is participating and attending the groups if they are held at local facilities or programs.

Among those who completed the survey, it was interesting to note that there was agreement regarding the importance of the role of

traditional/cultural aspects (beliefs, ceremonies, and treatment from a traditional practitioner/medicine man) in living with cancer. The results indicated a slightly higher average in comparison to these same items when related to their importance in treatment. This may reflect the participants' belief about the role of traditional/cultural practices as it relates to supporting the well-being of a person's spiritual/mental health and coping with a cancer diagnosis as opposed to physical treatment.

Over half of the interview and survey participants stated that they believed in the importance of a positive attitude in living with a cancer diagnosis would greatly impact their ability to live a longer life. There were many who emphasized that one of the most important influences in maintaining a positive outlook and attitude was the role of spirituality and/or their faith in God.

There has been a recent focus about health-related quality of life (HRQOL) and the role of spirituality and coping among cancer survivors (Kagawa-Singer, Padilla and Giwa 2010; Shevon-Harvey 2010; Hu 2008; Vachon 2008; Au 2007; Calhoun 2006) and as a result an increase in available resources and referral service networks for churches, pastors and spiritual leaders to effectively outreach to their communities. It may be helpful in enhancing the role of spiritual support identified as important by the participants, by providing resource information to pastors, churches and spiritual leaders in the community to enable them to effectively respond to the needs of cancer survivors and their families.

Cultural Consensus Analysis Critiques

There have been several criticisms with regard to the use of cultural consensus analysis based on the varying views of culture among anthropologists.

In *The Interpretation of Cultures* (1973), Geertz criticizes Goodenough's view of culture which Geertz labels "ethnoscience" (p. 11), or cognitive anthropology. Cultural consensus theory and methods are based on cognitive anthropology, which views cultural meaning as existing in the minds of individuals. Geertz views cultural meaning as public, or existing in an external sense (White 1959). Geertz further accuses cognitive anthropology of reducing culture, or categorizing it into (D'Andrade 1999) something that it is not and given cultural forces of its own (Geertz 1973). And finally, Geertz also claims that by limiting culture to shared cultural knowledge, culture is reduced to only a fraction of its true essence

A second criticism of consensus analysis has been its limiting assumption of a single unified culture. Handwerker (2002), and Caulkins and Hyatt (1999) have argued that culture, particularly in contemporary global contexts, is fluid, contested, and multidimensional. They suggest that important cultural diversity around a domain can exist within a culture group, and that elements of cultural models may extend across groups. Additionally, individuals may draw on multiple cultural models in different contexts and social interactions.

Handwerker (2002), and Caulkins and Hyatt (1999), have shown that weak consensus, moderately high alternate factors, differentially distributed factor loadings, and negative factor loadings can all be useful data, and can signal cultural contestation, subcultural groups, and cultural 'turbulence.' So, they propose that rather than dismiss models that fail to meet the conditions of formal consensus analysis, these models can be interpreted in a more general fashion, and can reveal important information about the distribution and consistency of cultural information. In other words, much more may be learned from the disagreement or lack of sharing within and across cultures rather than limiting a focus or emphasis on the shared agreement or cultural consensus.

Limitations of the Study

First, the sample size was not large enough to do extensive analysis based on additional variables. Another approach to address this limitation would have been to focus on a specific type of cancer. This may have resulted in stronger agreement in specific domains (i.e. prevention, treatment). The demographic information provided from the additional 30 individuals in the community-wide survey provided information that there was knowledge of a variety of different types of cancer diagnoses that had occurred in the community, including breast, prostate, leukemia, pancreatic, and cervical cancer. However, the largest representation was breast cancer. Because each of these types of cancer have different approaches to reducing risk (prevention), causes and treatment, a focused

approach on specific cancers may have resulted in stronger agreement, as well as providing specific context to the type of cancer during the ethnographic interviews.

Second, the number of questions in the sub-domains on the community-survey limited the ability to do separate consensus analysis with each. This would have been challenging, however, as the 60 questions survey with the additional demographic questions took participants at least 30 – 40 minutes to complete. If it were longer, many community members may not have been willing to participate.

Third, the results from this project cannot be generalized to other American Indian/Alaska Native populations, as the project was developed and implemented, specifically to reflect the social/cultural/environmental influences related to the knowledge and beliefs about cancer in the community. However, the processes and the issues of tribal and community involvement at every stage can be generalized and applied in other communities. Another possible shared approach that could be compared with other American Indian/Alaska Native communities may be to do a comparison with communities who share a similarity in environmental exposure issues and concerns about cancer prevalence and incidence in their community. Additionally, the benefit of the application of cultural consensus and a mixed method approach in addressing cancer health disparities may be of equal benefit to other tribal communities.

Fourth, there is always a limitation of time on analysis of all the data gathered or the ability to respond to questions that arise because of the results.

Implications

Policy

The primary environmental concerns that were related to exposure to possible chemical or toxic substances from the cement plant (i.e. airborne dust and particles) and the Phelps Dodge copper mine (i.e. tailings, leach ponds) are valid concerns that have been expressed by community members. It has been well documented that a public health issue that is currently confronting the Southwestern region of the United States is the exposure to hazardous waste, specifically arsenic, chlorinated hydrocarbon, and mine tailings contamination due to the extensive history of mining in the state (UA, 2008). Mine tailings cover 300,000 acres in Arizona alone (UA, 2008).

For Native peoples, environmental justice includes a different set of issues than it does for other affected groups. Environmental justice requires attention to the interrelated cultural, spiritual, social, ecological, economic, and political dimensions of environmental issues. For tribal communities in the United States, environmental justice cannot be discussed apart from recognition of tribes' unique legal and political status – tribes are sovereign governments, with rights to and management authority over tribal lands and resources (O'Neill 2003).

Tribes have been aggressive in protecting their right to self-governance and self-determination, often in the face of considerable opposition. The assertion of sovereignty has become increasingly evident and critical in the area of environmental management (McNally 1996).

There may be potential policy implications with regard to the Yavapai-Apache Nation's response to environmental exposures in their community, including toxic waste exposure due to the location of mine tailing piles located in close proximity to reservation communities and possible seepage into the water supply; dust and/or particulates hazardous to the air quality and its affects on residents.

In discussion with tribal leadership, the Tribal Council has established a Clean Air Act for their community; however, other environmental laws that may be needed to address potential hazardous waste exposure have not been developed or implemented. Additionally, it is unclear if there is current capacity or technical assistance to ensure monitoring to ensure compliance with defined standards. Identification of available resources in technical assistance and infrastructure support may be needed in developing an effective approach to address these environmental concerns that may contribute to increasing cancer risks in the community.

It may be in the tribe's best interest to review and enhance, as appropriate, any existing tribal environmental policy specific to air pollutants and toxic waste exposure and remediation options, as well as

assess environmental policy that currently does not exist but is needed to address the community's concern about potential environmental exposures that may contribute to an increased risk in cancer to community members.

A suggested first step in responding to the community's concerns would be to contact the Superfund Basic Research Program (SBRP) at the University of Arizona. It is a multi-university program supported by the National Institute of Environmental Health Sciences (NIEHS), which is one of the institutes at the National Institutes of Health (NIH). The SBRP's stated underlying research is "detecting, assessing, and ameliorating environmental pollution and determining the impact of environmental pollution on human health" (UA, 2008). The program could be contacted to inquire 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. If that is not a function of the program, they may be able to provide a referral to resource agencies or programs that could provide similar assessment services.

A second environmental exposure concern was related to the impact of nuclear testing that took place in the 1950's in Nevada and the "downwind" effects to community residents. As stated previously, there were several participants who were aware of community members or their families who have received compensation through RECA due to a diagnosis or death due to cancer. Although the exposure to radiation due

to nuclear weapons testing in Nevada is a known cause of cancer in the region, there has been little or no emphasis by the RECA program to provide education to community members on the importance of seeking annual cancer screening, or providing an awareness of possible symptoms that should prompt them to seek immediate medical care. A cancer education program needs to be developed that specifically outreaches to the senior or elder population and their families providing educational information, including available cancer screening resources.

An even larger implication to the discussions of environmental justice and racism are the cancer health disparities that have resulted in tribal and rural communities due to the exposure to nuclear fallout from testing. Narratives of “downwinders” not only attests to the affected communities awareness of the issues and its very real threats, but unfortunately serves as a reference point to the larger issues of inequality, exploitation, lack of protection and remediation. It is unfortunate that even in the RECA’s outreach program to tribal communities that the focus has been on financial settlement to avoid further litigation, rather than on the additional effort of educating communities about their exposure risk and facilitating their access to appropriate education, screening and treatment as needed. Without appropriate access to needed preventive and treatment services, the current status of late diagnosis due to limited access and lack of screening will continue the disparity of lower survival rates and higher mortality.

Programmatic

The community's knowledge and experience of cancer has been one of late diagnosis and very little experience or knowledge of community members surviving and living well after a diagnosis. Most acknowledged that they don't know if cancer can be prevented and lack current health education regarding: the prevention of cancer; the availability of cancer screening tests and why they are needed on a regular basis; what successful treatment options are available; and awareness of what support services or programs are available to cancer survivors and their families.

Based on the research results, there is a clearly a need for the development of a comprehensive cancer education program including a focus on different types of cancer as reported for this community. 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.

Enhancement of Existing Services

An effective approach to providing cancer education and prevention information to the community may be to integrate a prevention message within existing tribal programs that support living healthy lifestyles of diet and exercise, including – the wellness program, the tobacco cessation

program, elder's activities, and the cultural lifeways program activities.

This would be cost effective in terms of staff time, but would also utilize an effective risk reduction focus emphasizing behavioral change in establishing a healthy diet and active lifestyle in the prevention of chronic disease, including diabetes and cancer.

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.).

It may be appropriate for the tribal medical center to provide general screening information (i.e. types, recommended age guidelines), screening provided at their facility, as well as resource information for additional required screening that is available at other local or IHS facilities.

It would also be an important component to carry out an assessment of the current cancer education needs for tribal health program and medical center staff, to make certain they have the information needed to enhance their outreach and service activities in the community.

Future Research

In the application of CBPR principles in continuing to enhance the research relationship with the community, any potential research projects should originate from and at the request of the community.

During the course of completing this study, there has been an initial discussion about a potential research project that has been suggested by the tribal tobacco prevention program.

During the ethnographic interviews, there was a concern that had been expressed regarding tobacco use and its potential in causing cancer in a unique cultural context. There are members of the community who regularly participate in traditional ceremonies in different tribal cultures held outside the community. Recent changes have occurred that have resulted in an increased usage of commercial tobacco in substitution of traditional herbal tobacco in ceremonial practice. The tribal tobacco prevention program is interested in assessing the impact that these changes may have on increasing the risk of cancer among community members and developing a prevention program that is specifically focused on providing culturally responsive prevention information and potentially reintroducing the use of herbal/traditional tobacco as a less harmful alternative. They are currently working in partnership with the tribe's cultural resource program in potentially growing traditional tobacco to increase access for traditional practice purposes.

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 the 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 conducting research to address health disparities.

REFERENCES

- 2000 National Health Interview Survey (NHIS) Public use Data Release.*
Ed. Division of Health Interview Statistics, National Center for Health Statistics. Centers for Disease Control and Prevention, U.S. Department of Health and Human Services, 2002. Print.
- Acton, K. J., et al. "Diabetes Prevalence among American Indians and Alaska Native and the overall Population - United States, 1994-2002." *Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report* 52.30 (2003): 702-4. Print.
- Ambler, M. M. "Breaking the Iron Bonds: Indian Control of Energy Development." *History (Washington)* 19.4 (1991): 152-3. Print.
- Anders, G. C. "A Critical Analysis of the Alaska Native Land Claims and Native Corporate Development." *Native Americans and Public Policy.* Eds. FJ Lyden and LH Legters. Pittsburgh, Pa.: University of Pittsburgh Press, 1992. 85-98. Print.
- Arizona Cancer Facts and Figures 2004-2005: A Sourcebook for Planning and Implementing Programs for Cancer Prevention and Control.*
Phoenix, AZ: American Cancer Society, Great West Division, Inc., 2004. Print.
- The Arizona Comprehensive Cancer Control Plan :Working Together to Reduce Cancer.* Phoenix, Ariz.: Arizona Dept. of Health Services, Division of Public Health, Office of Chronic Disease Prevention and Nutrition Services, 2005. Print.
- "Arsenic in drinking water." May 2001 2001.Web.
<<http://www.who.int/mediacentre/factsheets/fs210/en/>>.
- Au, A. "Ethnicity and Spirituality in Breast Cancer Survivors." *Journal of Cancer Survivorship* 1.3 (2007): 212-25. Print.
- Baer, R. D., et al. "A Comparison of Community and Physician Explanatory Models of AIDS in Mexico and the United States." *Medical Anthropology Quarterly* 18.1 (2004): 3-22. Print.
- Barnes, P. M., P. F. Adams, and E. Powell-Griner. "Health Characteristics of the American Indian or Alaska Native Adult Population: United States, 2004-2008." *National Health Statistics Reports* (20).20 (2010): 1-22. Print.

- "Basic Information: polychlorinated biphenyl (PCB)." 2010. Web. 2/20/11
<<http://www.epa.gov/wastes/hazard/tsd/pcbs/pubs/about.htm>>.
- Beach, M. "Phoenix Cement: 50 and Growing." *Verde Independent*
10/14/2009 2009. Web.
<<http://verdenews.com/main.asp?SectionID=1&subsectionID=1&articleID=33133>>.
- Bechle, Greg. "Mountains of Cyanide." *Progressive* 54.9 (1990): 14. Print.
- Bernard, H. R. *Research Methods in Anthropology : Qualitative and Quantitative Methods*. Walnut Creek, CA: AltaMira Press, 2002. Print.
- . *Research Methods in Cultural Anthropology*. Third ed. Newbury Park, Ca: Sage, 2001. Print.
- Beyer, N. "Why there are big cancer concerns in one Arizona community." November 28 2009. Web.
- Bhatia, K., and P. Anderson. *An Overview of Aboriginal and Torres Strait Islander Health: Present Status and Future Trends*. Canberra, Australia, 1995. Print.
- Bordewich, F. M., and F. Scholder. *Killing the White Man's Indian : Reinventing Native Americans at the End of the Twentieth Century*. New York: Doubleday, 1996. Print.
- Borgatti, S. P., M. G. Everett, and L. C. Freeman. *UCINET for Windows: Software for Social Network Analysis*. Windows Vol. Harvard Analytic Technologies, 2002. Print.
- Borgatti, S. P. "Elicitation Techniques." *Enhanced Ethnographic Methods*. Eds. J. J. Schensul, et al. Walnut Creek, CA: AltaMira Press, 1999. Print.
- Boss, L. *Cancer*. Rockville, MD, 1986. Print.
- Boster, J. S. "Exchange of Varieties and Information between Aguaruna Manioc Cultivators." *American Anthropologist* 88.2 (1986): 428-36. Print.
- Braatz, Timothy. *Surviving Conquest: A History of the Yavapai Peoples*. Lincoln and London: University of Nebraska Press, 2003. Print.

- . "The Yavapais: A History of Indians in North-Central Arizona to 1910." Ph.D. Arizona State University, 1997. Print.
- Braun, K. L., M. A. Look, and J. A. Tsark. "High Mortality Rates in Native Hawaiians." *Hawaii Medical Journal* 54.9 (1995): 723-9. Print.
- Broderson, Tom. "Compensation Available to Fallout Cancer Victims." *Sharlot Hall Museum: Days Past* 2002. Web. January 2010 <<http://www.justice.gov/civil/torts/const/reca/about.htm>>.
- Brugge, D., and M. Missaghian. "Protecting the Navajo People through Tribal Regulation of Research." *Science and Engineering Ethics* 12.3 (2006): 491-507. Print.
- Bullard, R. D., and J. R. Feagin. "Racism and the City." *Urban Life in Transition*. Eds. Mark Gottdiener and C. G. Pickvance. 39 Vol. Newbury Park, Calif.: Sage, 1991. 55-76. Print.
- Bullard, R. D. *Confronting Environmental Racism :Voices from the Grassroots*. 1st ed. Boston, Mass.: South End Press, 1993. Print.
- . *Dumping in Dixie :Race, Class, and Environmental Quality*. Boulder: Westview Press, 1990. Print.
- . "Environmental Justice in the 21st Century: Race Still Matters." *Phylon* 49.3 (2001): 151. Print.
- . "Environmentalism and Public Policy: Environmental Justice: Grassroots Activism and its Impact on Public Policy Decision Making." *Journal of Social Issues* 56.3 (2000): 555-78. Print.
- . "Solid Waste Sites and the Black Houston Community." *Sociological Inquiry* 53.2-3 (1983): 2-3. Print.
- Burhansstipanov, L., and C. M. V. Dresser. *Documentation of the Cancer Research Needs of American Indians and Alaska Natives*. 94-3603 Vol. Bethesda, Md.: Cancer Control Science Program, Division of Cancer Prevention and Control, National Cancer Institute, 1994. Print.
- Burhansstipanov, L., et al. "An Innovative Path to Improving Cancer Care in Indian Country." *Public Health Reports (1974)* 116.5 (2001): 424-33. Print.
- Burns, Mike. *The Journey of a Yavapai Indian, A 19th Century Odyssey*. Princeton, NJ: Elizabeth House, 2002. Print.

- Calhoun, E. "A Qualitative Evaluation of a Faith-Based Breast and Cervical Cancer Screening Intervention for African American Women." *Health Education & Behavior* 33.5 (2006): 643-63. Print.
- Campbell, G. R. "The Changing Dimension of Native American Health: A Critical Understanding of Contemporary Native American Health Issues." *American Indian Culture and Research Journal* 13.3 (1989): 1-20. Print.
- "Cancer Prevention Overview." 2/24/2011 2011.Web.
<<http://www.cancer.gov/cancertopics/pdq/prevention/overview/patient/page3>>.
- Carson, D. K., and C. Hand. "Dilemmas Surrounding Elder Abuse and Neglect in Native American Communities." *Understanding Elder Abuse in Minority Populations*. Ed. T. Tatar. Philadelphia: Brunner/Mazel, 1999. 161-184. Print.
- Caulkins, D., and S. Hyatt. "Using Consensus Analysis to Measure Cultural Diversity in Organizations and Social Movements." *Field Methods* 11.1 (1999): 5-26. Print.
- Chavez, L. R., et al. "Beliefs Matter: Cultural Beliefs and the use of Cervical Cancer-Screening Tests." *American Anthropologist* 103.4 (2001): 1114-29. Print.
- Chavez, L. R., et al. "Understanding Knowledge and Attitudes about Breast Cancer. A Cultural Analysis." *Archives of Family Medicine* 4.2 (1995): 145-52. Print.
- Christopher, Suzanne S. "Recommendations for Conducting Successful Research with Native Americans." *Journal of Cancer Education* 20 (2005): 47-51. Print.
- Churchill, W. *A Little Matter of Genocide : Holocaust and Denial in the Americas, 1492 to the Present*. San Francisco: City Lights Books, 1997. Print.
- Churchill, W., and Winona LaDuke. "Native America: The Political Economy of Radioactive Colonialism." *Critical Sociology* 13.3 (1986): 51-78. Print.
- Clark, B. B. "The Indigenous Environmental Movement in the United States: Transcending Borders in Struggles Against Mining,

- Manufacturing, and the Capitalist State." *Organization & Environment* 15.4 (2002): 410-42. Print.
- Clinton, W. J., "Federal actions to address environmental justice in minority populations and low-income populations Executive Order 12898." 1994.Web.
- Cobb, N., P. A. Wingo, and B. K. Edwards. "Introduction to the Supplement on Cancer in the American Indian and Alaska Native Populations in the United States." *Cancer* 113.s5 (2008): 1113-6. Print.
- Coder, C., et al. "Chi Ch'll (Acorns): Dissolution of Traditional Dilzhe'e Gathering Practice(s) due to Federal Control of the Landscape." *USDA Forest Service Proceedings RMRS-P-36* (2005): 277-281. Print.
- Collins, N. B. "Nuclear Waste in Indian Country: A Paradoxical Trade." *Law & Inequality* 12 (1993): 267. Print.
- Colquette, K. M., and E. A. Robertson. "Environmental Racism: The Causes, Consequences, and Commendations." *Tulane Environmental Law Journal* 5 (1991): 153. Print.
- "Community Health Representative Program." December 2010 2010.Web. <<http://www.ihs.gov/NonMedicalPrograms/chr/index.cfm>>.
- Corbusier, W. H., and R. Wooster. *Soldier, Surgeon, Scholar :The Memoirs of William Henry Corbusier, 1844-1930*. Norman: University of Oklahoma Press, 2003. Print.
- Curbow, B. "The Ferrell/Hassey Dow Article Reviewed." *Oncology* 11.4 (1997): 572. Print.
- D'Andrade, R. G. "A Cognitivist's View of the Units Debate in Cultural Anthropology." *Cross-Cultural Research* 35.2 (2001): 242-57. Print.
- . "Comments to Brumann's 'Writing for Culture'." *Current Anthropology* 40 (1999) Print.
- . "Cultural Meaning Systems." *Culture Theory: Essays on Mind, Self, and Emotion.*, 1984. Print.
- . *The Development of Cognitive Anthropology*. Cambridge: Cambridge University Press, 1995. Print.

- Davis, J. D., and K.Y. Keemer. *A Brief History of and Future Considerations for Research in American Indian and Alaska Native Communities*. Distributed by ERIC Clearinghouse, 2002. Print.
- Dressler, W. W., and J. R. Bindon. "The Health Consequences of Cultural Consonance: Cultural Dimensions of Lifestyle, Social Support, and Arterial Blood Pressure in an African American Community." *American Anthropologist* 102.2 (2000): 244-60. Print.
- Dressler, W. W., M. C. Balieiro, and J. E. Dos Santos. "Culture, Socioeconomic Status, and Physical and Mental Health in Brazil." *Medical Anthropology Quarterly* 12.4 (1998): 424-46. Print.
- Dressler, W. W. "Medical Anthropology: Toward a Third Moment in Social Science?" *Medical Anthropology Quarterly* 15.4 (2001): 455-65. Print.
- . "Modeling Biocultural Interactions in Anthropological Research: An Example from Research on Stress and Cardiovascular Disease." *Yearbook of Physical Anthropology* 38 (1995): 27-56. Print.
- . "What's Cultural about Biocultural Research?" *Ethos (Berkeley, Calif.)* 33.1 (2005): 20-45. Print.
- Duncan, P. "Environmental Racism: Recognition, Litigation, and Alleviation." *Tulane Environmental Law Journal* 6 (1992): 317. Print.
- Eliminating Health Disparities in the United States*. U.S.: Health Resources and Services Administration, 2000. Web. December 9, 2009.
- "Environmental Justice: Basic Information and Background." March 4, 2011. Web.
<<http://www.epa.gov/compliance/environmentaljustice/basics/ejbackground.html>>.
- Epey, D., et al. "Methods for Improving Cancer Surveillance Data in American Indian and Alaska Native Populations." *Cancer* 113.s5 (2008): 1120-30. Print.
- Epey, D., R. Paisano, and N. Cobb. "Regional Patterns and Trends in Cancer Mortality among American Indians and Alaska Natives, 1990-2001." *Cancer* 103.5 (2005): 1045. Print.

- Final Guidance for Incorporating Environmental Justice Concerns in EPA's NEPA Compliance Analysis*. Eds. A. Totten and B. Dickerson. Washington, D.C.: U.S. Environmental Protection Agency, 1998. Web.
- Foust, R. D., Jr., et al. "Groundwater Arsenic in the Verde Valley in Central Arizona, USA." *Applied Geochemistry* 19 (2004): 251-255. Print.
- Freeman, H. P., and B. K. Wingrove, eds. *Excess Cervical Cancer Mortality: A Marker for Low Access to Health Care in Poor Communities*. 05-5282 Vol. Rockville, MD: National Cancer Institute, Center to Reduce Cancer Health Disparities, 2005. Print.
- Garro, L. C. "Explaining High Blood Pressure: Variation in Knowledge about Illness." *American Ethnologist* 15.1 (1988): 98-119. Print.
- Garro, L. C. "Intracultural Variation in Folk Medical Knowledge: A Comparison between Curers and Noncurers." *American Anthropologist* 88.2 (1986): 351-70. Print.
- Geertz, C. *The Interpretation of Cultures: Selected Essays*. New York: Basic Books, 1973. Print.
- Gifford, E. W. "Northeastern and Western Yavapai Myths." *The Journal of American Folk-Lore* 46.182 (1933): 347-415. Print.
- Glaser, B. G. "The Discovery of Grounded Theory: Strategies for Qualitative Research." *Qualitative Research Journal* 6.2 (2007) Print.
- Goldman, B. A., et al. *Toxics [Sic] Wastes and Race Revisited: An Update of the 1987 Report on the Racial and Socioeconomic Characteristics of Communities with Hazardous Waste Sites*. Washington, D.C.: Center for Policy Alternatives, 1994. Print.
- Good, B. *Medicine, Rationality, and Experience: An Anthropological Perspective*. 1990 Vol. Cambridge England; New York: Cambridge University Press, 1994. Print.
- Good, B. J., and M. J. D. Good. "The Meaning of Symptoms: A Cultural Hermeneutic Model for Clinical Practice." *The Relevance of Social Science for Medicine*. 1980. 165-196. Print.
- Goodenough, W. H. "Ethnographic Field Techniques." *Handbook of Cross-Cultural Psychology*. Ed. HC Triandis. Boston: Allyn and Bacon, 1980. 29-55. Print.

- Hall, P. M. *Northern Arizona Public Health Nursing Project - Community Profiles: Tonto Apache Reservation, Yavapai-Apache Nation, Yavapai Prescott Tribe*. Phoenix Indian Medical Center, 2001. Print.
- Hampton, J., and J. Henderson. "Report of the Data Working Group Meeting: Issues for American Indian and Alaska Native Populations." *Intercultural Cancer Council*. 1999. Print.
- Hampton, J. "Cancer Prevention and Control in American Indians/Alaska Natives." *American Indian Culture and Research Journal* 16.3 (1992): 41. Print.
- . "The Heterogeneity of Cancer in Native American Populations." *Minorities and Cancer*. Ed. L. Jones. New York: Springer-Verlag, 1989. Print.
- Handwerker, W. P. and Wozniak, D.F. "Sampling Strategies for the Collection of Cultural Data: An Extension of Boas's Answer to Galton's Problem." *Current Anthropology* 38.5 (1997): 869-75. Print.
- Handwerker, W. P. "The Construct Validity of Cultures: Cultural Diversity, Culture Theory, and a Method for Ethnography." *American Anthropologist* 104.1 (2002): 106. Print.
- Hannerz, U. *Cultural Complexity : Studies in the Social Organization of Meaning*. New York: Columbia University Press, 1992. Print.
- Harmon, A. "Indian Tribe Wins Fight to Limit Research of its DNA." *The New York Times* 1 (2010) Print.
- Harrington, J. P. "A Yuma Account of Origins." *American Folklore Society* 21.82 (1908): 324-348. Print.
- Havasupai Tribe vs. Arizona State University*. Case No. CV2005-013190 Vol. Superior Court of Arizona, Maricopa County Web. 04/15/2009.
- Healthy People 2010, and United States. *Healthy People 2010*. Conference ed. Washington, DC: U.S. Dept. of Health and Human Services, 2000. Print.
- Heckler, Margaret M. *Report of the Secretary's Task Force on Black and Minority Health. Vol. 1, Executive Summary*. U.S. Department of Health and Human Services, 1985. Print.

- Horner, R. R. "Cancer Mortality in Native Americans in North Carolina." *American Journal of Public Health* (1971) 80.8 (1990): 940-4. Print.
- Hu, J. "Symptom Distress, Spirituality, and Quality of Life in African American Breast Cancer Survivors." *Cancer Nursing* 31.1 (2008): 21. Print.
- Hundahl, S. S. A. "Perspective: National Cancer Institute Summary Report about Estimated Exposures and Thyroid Doses Received from Iodine 131 in Fallout After Nevada Atmospheric Nuclear Bomb Tests." *CA: a Cancer Journal for Clinicians* 48.5 (1998): 285-98. Print.
- "IHS Fact Sheets: Indian Health Disparities." Web. January 2011 <<http://info.ihs.gov/Disparities.asp>>.
- IHS. *January 2000, Interim Report to Congress: Special Diabetes Program for Indians, IHS National Diabetes Program*. Albuquerque, NM: Indian Health Service, 2000. Print.
- Israel, B. A., et al. "Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health." *Annual Review of Public Health* 19.1 (1998): 173-202. Print.
- Iverson, P. *Carlos Montezuma and the Changing World of American Indians*. Albuquerque: University of New Mexico Press, 1982. Print.
- Joe, J. R. "Editorial." *Health Care for Women International* 20.5 (1999): 443-444. Print.
- . "The Rationing of Healthcare and Health Disparity for the American Indians/Alaska Natives." *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Eds. B. D. Smedley, A. Y. Stith, and A. R. Nelson. Washington, D.C.: The National Academies Press, 2003. 528-551. Print.
- Johnson, C. K. "A Sovereignty of Convenience: Native American Sovereignty and the United States Government's Plan for Radioactive Waste on Indian Land." *Social Change* 303 (1993): 310. Print.
- Johnson, J. C., ed. *Selecting Ethnographic Informants*. 22 Vol. Newbury Park: Sage Publications, 1990. Print.
- Justice, J. "Cancer in American Indians and Alaska Natives." Tucson, AZ: Native American Research and Training Center, 1990. Print.

- . *Contrasting Cancer Patterns in Two American Indian Tribes*. Tucson, AZ: University of Arizona, Native American Research and Training Center, 1988. Print.
- Kagawa-Singer, M., G. V. Padilla, and K. Ashing-Giwa. "Health-Related Quality of Life and Culture." *Seminars in Oncology Nursing* 26.1 (2010): 59-67. Print.
- Kaufert, J. M. "Cultural Mediation in Cancer Diagnosis and End of Life Decision-Making: The Experience of Aboriginal Patients in Canada." *Anthropology & Medicine* 6.3 (1999): 405-21. Print.
- Kaur, J. S. "Home Care for Native American Cancer Patients: An Oncologist's Perspective." *Alaska Medicine* 37.4 (1995): 132, 156. Print.
- . "The Potential Impact of Cancer Survivors on Native American Cancer Prevention and Treatment." *BMC Cancer* 78.s7 (1996): 1578. Print.
- Kleinman, A. *The Illness Narratives : Suffering, Healing, and the Human Condition*. New York: Basic Books, 1988. Print.
- Kunitz, S. S. J. "Ethics in Public Health Research: Changing Patterns of Mortality among American Indians." *American Journal of Public Health* (1971) 98.3 (2008): 404-11. Print.
- LaDuke, W. *All our Relations: Native Struggles for Land and Life*. Cambridge, MA; Minneapolis, MN: South End Press; Honor the Earth, 1999. Print.
- LaDuke, W. "Indigenous Environmental Perspectives: A North American Primer." *Northeast Indian Quarterly* 9.2 (1992): 52-71. Print.
- Lanier, A. P., et al. *Cancer in Alaska Natives 1969-1993, a 25 Year Report*. Anchorage, AK: Alaska Area Native Health Services, Indian Health Services, U.S. Public Health Service. 1996. Print.
- Larsson, S., and N. W. Orsini. "Diabetes Mellitus and Risk of Colorectal Cancer: A Meta-Analysis." *JNCI : Journal of the National Cancer Institute* 97.22 (2005): 1679-87. Print.
- Lavelle, M, and M. Coyle. "Unequal Protection: The Racial Divide in Environmental Law." *The National Law Journal* 15.3 (1992): S1. Print.

- Lee, C. "The First National People of Color Environmental Leadership Summit, the Washington Court on Capitol Hill, Washington, D.C., October 24-27, 1991 : Proceedings." New York, N.Y.: United Church of Christ, the Commission for Racial Justice; 1992. Print.
- Lenth, R. V. "Java Applets for Power and Sample Size [Computer software]." (2006-9).Web. 10/04/10
<<http://www.stat.uiowa.edu/~rlenth/Power>>.
- Leslie, C. "Backing into the Future." *Medical Anthropology Quarterly* 15.4 (2001): 428-39. Print.
- Lester, D. "The Environment from an Indian Perspective." *EPA Journal* 12. (Jan/Feb.) (1986): 27-28. Web. 2/20/11.
- Lewis, D. R. "Native Americans and the Environment: A Survey of Twentieth-Century Issues." *American Indian Quarterly* 19.3 (1995): 423. Print.
- "Lifetime risk of developing or dying from cancer." 8/10/2010 2010.Web.
<<http://www.cancer.org/Cancer/CancerBasics/lifetime-probability-of-developing-or-dying-from-cancer>>.
- Lucas, C. A. "'Toxin Defense' Successful." *National Law Journal*. May 1, 1989 (1989): 9. Print.
- Mahoney, M. C., and A. M. Michalek. "A Meta-Analysis of Cancer Incidence in United States and Canadian Native Populations." *International J Epidemiology* 20.2 (1991): 323-7. Print.
- Mann, E. *L.A.'s Lethal Air :New Strategies for Policy, Organizing, and Action*. Los Angeles: Labor/Community Strategy Center, 1991. Print.
- Manson, S. M., et al. "Access, Relevance, and Control in the Research Process: Lessons from Indian Country." *Journal of Aging and Health* 16.5 Suppl (2004): 58S-77S. Print.
- McMullin, J. M., et al. "Influence of Beliefs about Cervical Cancer Etiology on Pap Smear use among Latina Immigrants." *Ethnicity & Health* 10.1 (2005): 3-18. Print.
- McNally, M. "Indian Reservations, Solid Waste and Development: Some Difficult Choices." *Environments* 23 (1996): 1. Print.

- Mohai, P. "Is there a "Race" Effect on Concern for Environmental Quality?" *Public Opinion Quarterly* 62.4 (1998): 475. Print.
- Monson, P. C. "Radioactive Air Pollution from Uranium Mining: Regulatory Abdication in the Face of Scientific Uncertainty." *Environmental Law (Portland, Ore.)* 13 (1982): 545. Print.
- Morrison, J. "Mercury Poisoning Real Threat to Minnesotans." *Indian Country Today*. A3. Print. December 15 1994.
- National Cancer Institute. *Estimated Exposures and Thyroid Doses Received by the American People from Iodine-131 in Fallout Following Nevada Atmospheric Nuclear Bomb Tests*. Washington, D.C.: National Cancer Institute, National Institute of Health, 1997. Print.
- National Tribal Budget Recommendations for the Indian Health Service: Fiscal Year 2013 Budget*. Washington, D.C.: National Indian Health Board, 2011. Print.
- Nutting, P. A., et al. "Cancer Incidence among American Indians and Alaska Natives, 1980 through 1987." *American Journal of Public Health* (1971) 83.11 (1993): 1589-98. Print.
- Ogunwole, Stella U. *The American Indian and Alaska Native Population, 2000*. C 2 KBR/01-15 Vol. Washington, D.C.: U.S. Dept. of Commerce, Economics and Statistics Administration, U.S. Census Bureau, 2002. Print.
- O'Neill, C. A. "Risk Avoidance, Cultural Discrimination, and Environmental Justice for Indigenous Peoples." *Ecology Law Quarterly & Currents* 30.1 (2003): 1. Print.
- Paisano, R., N. Cobb, and D. K. Espey. "Cancer Mortality among American Indians and Alaska Natives-United States, 1994-1998." *MMWR Morbidity and Mortality Weekly Report* 52.30 (2003): 704. Print.
- Parezo, N. J. "Strengthening Sovereignty through Ethical Research". *Annual Meeting of the Society for Applied Anthropology*. Dallas, Texas. 2004. Print.
- Pavkov, M. M. E. "Changing Patterns of Type 2 Diabetes Incidence among Pima Indians." *Diabetes Care* 30.7 (2007): 1758-63. Print.

Perez, C. A., et al. "Uterine Cervix." *Principles and Practice of Gynecologic Oncology*. Eds. William J. Hoskins, Carlos A. Perez, and Robert C. Young. Philadelphia: J.B. Lippincott, 1992. 623-682. Print.

Piner, J. M., and T. W. Paaradis. "Beyond the Casino: Sustainable Tourism and Cultural Development of Native American Lands." *Tourism Geographies* 6.1 (2004): 80-98. Print.

"Poor health care access not to blame for high death rates among American Indian women with breast cancer." 2011.Web.

Prucha, F. P. *Handbook for Research in American History: A Guide to Bibliographies and Other Reference Works*. Lincoln: University of Nebraska Press, 1994. Print.

"Radiation Exposure Compensation Program." November 2009. Web. <<http://www.justice.gov/civil/torts/const/reca/index.htm>>.

Radiation Exposure Compensation System - Claims to Date Summary of Claims Received by 2/27/11. U.S. Department of Justice, 2011. Web. February 27, 2011.

Reff, D. T. *Disease, Depopulation, and Culture Change in Northwestern New Spain, 1518-1764*. Salt Lake City: University of Utah Press, 1991. Print.

Regional Differences in Indian Health 1998-99. Rockville, MD: Department of Health and Human Services, Indian Health Service, 2000. Print.

Reis, P. "Obama Administration Strikes \$3.4 Billion in Indian Trust Lawsuit." *The New York Times*, sec. Energy and Environment: December 8, 2009. Web. <<http://www.nytimes.com/gwire/2009/12/08/08greenwire-obama-admin-strikes-34b-deal-in-indian-trust-l-92369.html>>.

Rhoades, E., A. J. D'Angelo, and W. B. Hurlburt. "The Indian Health Service Record of Achievement." *Public Health Reports (1974)* 102.4 (1987): 356-60. Print.

Richardson, L. C., and L. A. Pollack. "Therapy Insight: Influence of Type 2 Diabetes on the Development, Treatment and Outcomes of Cancer." *Nature Clinical Practice Oncology* 2.1 (2005): 48-53. Print.

Robinson, W. P. "Uranium Production and its Effects on Navajo Communities Along the Rio Puerco in Western New Mexico." *Race*

and the Incidence of Environmental Hazards :A Time for Discourse.
Eds. Bunyan I. Bryant and Paul Mohai. Boulder, Colo.: Westview
Press, 1992. 153. Print.

Rockwell, Susan L. "The Autobiography of Mike Burns, Yavapai Apache."
Ph.D. Arizona State University, 2001. Print.

Rogers, D. D. "Cancer Disparities Research Partnership in Lakota
Country: Clinical Trials, Patient Services, and Community Education
for the Oglala, Rosebud, and Cheyenne River Sioux Tribes."
American Journal of Public Health (1971) 95.12 (2005): 2129-32.
Print.

Romney, A. K., W. H. Batchelder, and S. C. Weller. "Recent Applications
of Cultural Consensus Theory." *The American Behavioral Scientist*
(*Beverly Hills*) 31.2 (1987): 163-77. Print.

Romney, A. K., et al. "Concepts of Success and Failure*." *Social Science*
Research 8.4 (1979): 302. Print.

Romney, A. K., S. C. Weller, and W. H. Batchelder. "Interpreting
Consensus: A Reply to Price." *American Anthropologist* 90 (1988):
161-3. Print.

Romney, A. K., S. C. Weller, and W. H. Batchelder. "Culture as
Consensus: A Theory of Culture and Informant Accuracy." *American*
Anthropologist 88 (1986): 313-38. Print.

Rosaldo, R. *Culture and Truth the Remaking of Social Analysis.* Boston
MA: Beacon, 1993. Print.

Rubin, P. "Indian Givers; the Havasupai Trusted the White Man to Help
with a Diabetes Epidemic. Instead, ASU Tricked them into Bleeding
for Academia." *New Times (Phoenix, Ariz.)* 32.126 (2004) Print.

Ruland-Thorne, K. *The Yavapai, the People of the Red Rocks, the People*
of the Sun. Sedona, AZ: Thorne Enterprises Publications, Inc., 1993.
Print.

Sahota, P. C. *Research Regulation in American Indian/Alaska Native*
Communities: Policy and Practice Considerations. National Congress
of American Indians, Policy Research Center, 2009. Web.
12/05/2009.

- "Salazar: Settlement Agreements with First Americans mark historic progress in reconciliation, empowerment." December 8, 2010. Web. <<http://www.bia.gov/idc/groups/public/documents/text/idc012557.pdf>>.
- Saltzstein, K. "Southwest's" Navajo Flu" Deadly but Not Navajo." *American Journalism Review* 15.8 (1993) Print.
- Schell, L. "Health Disparities and Toxicant Exposure of Akwesasne Mohawk Young Adults: A Partnership Approach to Research." *Environmental Health Perspectives* 113.12 (2005): 1826-32. Print.
- Schiffman, M., and A. Hildeshiem. "Cervical Cancer." *Cancer Epidemiology and Prevention*. Eds. D. Schottenfeld and J. Fraumeni. Third ed. New York, NY: Oxford University Press, 2006. 1044-1067. Print.
- "Scorecard: the pollution information site." September 2004 2004. Web. <<http://scorecard.org/index.tcl>>.
- Shaffer, M. "Havasupai Blood Samples Misused." *Indian Country Today (Oneida, N.Y.)* 23.39 (2004): B1. Print.
- Shevon H. I. "Exploring the Role of Spirituality in Self-Management Practices among Older African-American and Non-Hispanic White Women with Chronic Conditions." *Chronic Illness* 6.2 (2010): 111-24. Print.
- Shore, B. *Culture in Mind : Cognition, Culture, and the Problem of Meaning*. New York: Oxford University Press, 1996. Print.
- Simon, S. L., A. Bouville, and C. E. Land. "Fallout from Nuclear Weapons Tests and Cancer Risks - Exposures 50 Years Ago Still have Health Implications Today that Will Continue into the Future." *American Scientist* 94.1 (2006): 48-57. Print.
- Smedley, B. D., et al. *Unequal Treatment : Confronting Racial and Ethnic Disparities in Health Care*. Washington, D.C.: National Academies Press, 2003. Print.
- Smith-Morris, C. "Autonomous Individuals Or Self-Determined Communities? the Changing Ethics of Research among Native Americans." *Human Organization* 66.3 (2007): 327-336. Print.

- Steele, C. B., et al. "Surveillance for Health Behaviors of American Indians and Alaska Natives—Findings from the Behavioral Risk Factor Surveillance System, 2000–2006." *Cancer* 113.s5 (2008): 1131-41. Print.
- Stoffel, B. "We the People: American Indians and Alaska Natives in the United States: Census 2000 Special Reports." *Choice (Middletown)* 43.11/12 (2006): 2085. Print.
- Strickland, C. J. "The Importance of Qualitative Research in Addressing Cultural Relevance: Experience from Research with Pacific Northwest Indian Women." *Health Care for Women International* 20.5 (1999): 517-25. Print.
- Sturrock, K. K., and J. Rocha. "A Multidimensional Scaling Stress Evaluation Table." *Field Methods* 12.1 (2000): 49-60. Print.
- Suagee, D. B. "The Indian Country Environmental Justice Clinic: From Vision to Reality." *Vermont Law Review* 23 (1998): 567. Print.
- "Superfund Research Program: the University of Arizona." 2008.Web. <<http://superfund.pharmacy.arizona.edu/index.php>>.
- Supporting the Havasupai Indian Tribe in their Claim Against the Arizona Board of Regents regarding the Unauthorized use of Blood Samples and Research.* Tran. National Congress of American Indians. SAC-06-019 Vol., 2006. Web. 04/15/09.
- Taliman, Valerie. "Native Americans: U.S. Government's Guinea Pigs." *Sun-Sentinel (Fort Lauderdale, Fla.)* (1994): 2.F. Print.
- "Tohono O'Odham Faced with Mine Contamination." *Lakota Times*: B II. Print. August 19 1992.
- Tomsho, R. "Dumping Grounds: Indian Tribes Contend with some of Worst of America's Pollution --- Reservations Now Look Good to Promoters of Facilities for Toxic Waste Disposal --- Spirit of the River Weakens." *The Wall Street Journal. Eastern edition* (1990): PAGEA.1. Print.
- Trends in Indian Health: 2002-2003 Edition.* Rockville, MD: Department of Health and Human Services, Indian Health Service, 2009. Print.

- Tsosie, R. A. "Indigenous People and Environmental Justice: The Impact of Climate Change." *University of Colorado Law Review* 78 (2007): 1625. Print.
- United States. General Accounting Office. *Siting of Hazardous Waste Landfills and their Correlation with Racial and Economic Status of Surrounding Communities*. Washington, D.C.: GAO, 1983. Print.
- Vachon, M. L. "Meaning, Spirituality, and Wellness in Cancer Survivors." *Seminars in Oncology Nursing* 24.3 (2008): 218. Print.
- Varricchio, C. G., et al. "Quality of Life in Clinical Cancer Trials. Introduction." *Journal of the National Cancer Institute. Monographs* (20).20 (1996): vii-viii. Print.
- VERBI Software. *MAXQDA, Software for Qualitative Data Analysis*. 10 Vol. Sozialforschung GmbH, Berlin-Marburg-Amöneburg, Germany: 1989-2010. Web.
- Wallace, L., and A. Dellinger. "Injury Mortality among American Indian and Alaska Native Children and Youth - United States, 1989-1998." *Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report* 52.30 (2003): 697-701. Print.
- Waterstrat, E. *Hoomothya's Long Journey 1865-1897, the True Story of a Yavapai Indian*. Fountain Hills, AZ: Mount McDowell Press, 1998. Print.
- Weiner, D. "Health Beliefs about Cancer. among the Luiseno Indians of California." *Alaska Medicine* 35.4 (1993): 285-96. Print.
- Weller, S. C., et al. "Empacho in Four Latino Groups." *Medical Anthropology* 15 (1993): 109-36. Print.
- Weller, S. C., and A. K. Romney. *Systematic Data Collection*. 1988. Print.
- Weller, SC. "Cultural Consensus Theory: Applications and Frequently Asked Questions." *Field Methods* 19.4 (2007): 339-68. Print.
- West, P., et al. "Minority Anglers and Toxic Fish Consumption: Evidence of the State-Wide Survey of Michigan." *Race and the Incidence of Environmental Hazards : A Time for Discourse*. Eds. BI Bryant and P. Mohai. Boulder: Westview Press, 1992. 100-113. Print.

- White, L. "The Concept of Culture." *American Anthropologist* 61.2 (1959): 227-51. Print.
- Wilkinson, L. "SYSTAT." *Wiley Interdisciplinary Reviews: Computational Statistics* 2.2 (2010): 256-7. Print.
- Wilson, Robin N. "Disparities in Breast Cancer Treatment among American Indian, Hispanic and Non-Hispanic White Women Enrolled in Medicare." *Journal of Health Care for the Poor and Underserved* 18.3 (2007): 648-64. Print.
- Wingo, P. A., et al. "Breast Cancer Incidence among American Indian and Alaska Native Women: US, 1999-2004." *Cancer* 113.s5 (2008): 1191-202. Print.
- Wolsey, D. H., and J. E. Cheek. "Epidemiologic Patterns of Morbidity and Mortality." *Primary Care of Native American Patients :Diagnosis, Therapy, and Epidemiology*. Eds. James M. Galloway, Bruce W. Goldberg, and Joseph S. Alpert. Boston: Butterworth-Heinemann, 1999. 7-7-16. Print.
- Wood, M. C. "Indian Land and the Promise of Native Sovereignty: The Trust Doctrine Revisited." *Utah Law Review* 1994 (1994): 1471-1570. Web. 2/20/11.
- Wood, L., et al. "Vaccination Coverage Levels among Alaska Native Children Aged 19-35 Months - National Immunization Survey, United States, 2000-2001." *Centers for Disease Control and Prevention, Morbidity and Mortality Weekly Report* 52.30 (2003): 710-3. Print.

APPENDIX A

TRIBAL RESOLUTION IN SUPPORT OF THE RESEARCH PROJECT

RESOLUTION NO. 34 -10
OF THE GOVERNING BODY OF THE
YAVAPAI-APACHE NATION

**A Resolution Granting the Implementation of the Research Project-The Shared
Cultural Knowledge and Beliefs about Cancer in the
Yavapai-Apache Community**

WHEREAS: The Yavapai-Apache Tribal Council (“Council”) is empowered to represent the Yavapai-Apache Nation (“Nation”) and act on all matters that concern the health and welfare of the Nation, and to make decisions not inconsistent with or contrary to the Constitution of the Yavapai-Apache Nation; and

WHEREAS: The Council is the legislative body of the Nation empowered to enact laws, ordinances, and resolutions incidental to the exercise of legislative powers as provided by Article V(v) of the Nation’s Constitution; and

WHEREAS: Cancer is the second leading cause of deaths among American Indians and Alaska Natives over the age of 45 according to the Indian Health Services; and

WHEREAS: The Arizona Department of Health Services (“ADHS”) Cancer Registry in 2005 indicates that compared to Arizona’s average age-adjusted cancer mortality rate from 1999-2001(173.7/100,000), Yavapai County has the second highest death rate due to cancer (196.4/100,000) in the state; and

WHEREAS: A research project has been designed to apply cultural consensus theory and a combined approach utilizing qualitative and quantitative research techniques to identify and describe the community’s cultural knowledge and beliefs regarding cancer; and

WHEREAS: The research proposal has been reviewed by a Community Advisory Committee composed of the community members who will actively participate during the implementation of the project by: 1) reviewing and finalizing the final research proposal, 2) reviewing and approving of updates throughout the progress of the project, 3) providing input of needed changes or amendments, 4) reviewing and inputting of the final analysis and results, and 5) reviewing and approving of the final report for presentations and publications; and

WHEREAS: The researcher will work in partnership with the Community Advisory Committee to have a clear understanding of culturally sensitive issues and to ensure that the dignity and privacy of all tribal members is maintained; and

Page 1 of 3

A Resolution Granting the Implementation of Research Project-The Shared Cultural Knowledge and
Beliefs about Cancer in the Yavapai-Apache Community

Version #1 (2-23-10)

WHEREAS: About 15-20 key individuals in the community will be interviewed on a voluntary basis regarding their knowledge and beliefs about cancer, and an informed consent will be administered that will explain the study in detail and participants will be allowed to withdraw any time without any penalty; and

WHEREAS: A community survey will be developed and distributed to approximately 200 community members, 21 years of age and older; completion of the survey will be on a voluntary basis regarding their knowledge and beliefs about cancer, and an informed consent will be administered that will explain the study in detail and participants will be allowed to withdraw any time without any penalty; and

WHEREAS: The title of the study will be “The Shared Cultural Knowledge and Beliefs about Cancer In the Yavapai-Apache Community”; and

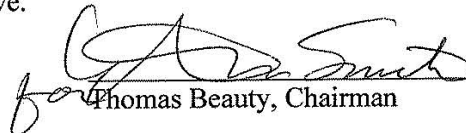
WHEREAS: The Council finds it in the best interests of the Nation to approve and authorize Elizabeth Brandt, Ph.D. and Cynthia Claus, MPH, of Arizona State University, School of Human Evolution and Social Change, to implement a research study to be completed in the Yavapai-Apache Community about the cultural knowledge and beliefs about cancer.

NOW THEREFORE BE IT RESOLVED that the Yavapai-Apache Nation Tribal Council, in Council assembled, at which a quorum is present, approves and authorizes Elizabeth Brandt, Ph.D. and Cynthia Claus, MPH, of Arizona State University, School of Human Evolution and Social Change, to conduct the research project “The Shared Cultural Knowledge and Beliefs about Cancer in the Yavapai-Apache Community”.

BE IT FINALLY RESOLVED that the Chairman, and Vice-Chairman, or either of them, are hereby authorized and approved to take such further action as deemed necessary or warranted to carry out the purposes and intent of this Resolution.

CERTIFICATION

I hereby certify that the foregoing resolution was adopted by an affirmative vote of the Tribal Council, with a quorum in attendance, presented for approval on February 25 2010, by a vote of 7 6 in favor, 1 opposed and 0 abstaining, pursuant to the authority contained under the Constitution of the Yavapai-Apache Nation as cited above.


for Thomas Beauty, Chairman

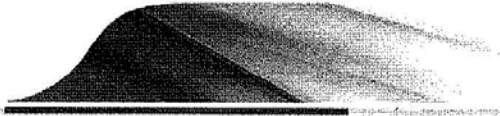
ATTEST:

Karla Reimer
Karla Reimer, Council Secretary

Approved as to form:
J. D. Guenther
Jerry D. Guenther


APPENDIX B

ARIZONA STATE UNIVERSITY IRB APPROVED EXEMPTION



Office of Research Integrity and Assurance

To: Elizabeth Brandt
MC

From: Mark Roosa, Chair 
Soc Beh IRB

Date: 03/15/2010

Committee Action: **Exemption Granted**

IRB Action Date: 03/15/2010

IRB Protocol #: 1003004925

Study Title: The Shared Cultural Knowledge and Beliefs about Cancer in the Yavapai-Apache Community

The above-referenced protocol is considered exempt after review by the Institutional Review Board pursuant to Federal regulations, 45 CFR Part 46.101(b)(2).

This part of the federal regulations requires that the information be recorded by investigators in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects. It is necessary that the information obtained not be such that if disclosed outside the research, it could reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, or reputation.

You should retain a copy of this letter for your records.

APPENDIX C

LETTER FROM ASU OFFICE OF RESEARCH INTEGRITY AND
ASSURANCE AND UNIVERSITY ADVOCATE FOR AMERICAN INDIANS
IN RESPONSE TO TRIBAL CONCERNS

March 23, 2010

Mr. Jerry D. Guenther
Assistant Attorney General
Yavapai-Apache Nation
2440 W. Datsi Street
Camp Verde, AZ 86322

Re: Dissertation Research Project – “The Shared Cultural Knowledge and Beliefs about Cancer in the Yavapai-Apache Community”

Dear Mr. Guenther,

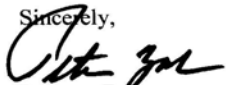
The ASU IRB has reviewed and approved the referenced study under the direction of ASU Professor Dr. Elizabeth Brandt and Ms. Cynthia Claus. The approval is contingent upon final authorization by the Yavapai-Apache Nation and relies upon the Tribal Resolution No 34 issued by the Governing Body of the Nation of February 25, 2010.

As part of the institutional approval ASU and the investigators agree that the Nation shall have the opportunity to provide final review of the information, results, findings and dissemination of the information presented resulting from this research and that the information shall remain the proprietary and confidential information of the Nation until such time as the Nation determines otherwise.

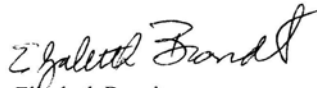
ASU requests that the Nation agree that the student investigator, Ms. Cynthia Claus may use the anonymously recorded data collected for educational purposes and for dissertation research once the Nation has reviewed the defense version and authorized use.

We look forward to collaborating with the Yavapai-Apache Nation on this collaborative survey project.

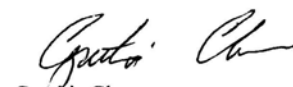
Sincerely,



Peterson Zan
Special Advisor to the President
American Indian Initiatives



Elizabeth Brandt
Professor, School of Human
Evolution and Social Change



Cynthia Claus
School of Human
Evolution and Social Change

APPENDIX D
KEY CONSULTANT'S INFORMED CONSENT

CONSENT FORM

Title: The Shared Cultural Knowledge and Beliefs about Cancer in the Yavapai-Apache Community

Introduction

You are invited to be in a research study. The study is called “The Shared Cultural Knowledge and Beliefs about Cancer in the Yavapai-Apache Community.” Please take your time to make your decision. It is important that you read and understand several general principles that apply to all who take part in this study:

- a) Taking part in the study is entirely voluntary;
- b) You will receive no direct benefit from taking part in the study, but knowledge may be gained from your participation that may benefit others in your community;
- c) You may withdraw from the study at any time without it affecting your current or future relationship with Arizona State University or with your health care provider, clinic or hospital.

Please read this form and feel free to ask any questions about this study with the individuals who explain it to you.

The researchers of the study are:

Elizabeth Brandt, Ph.D. – Principal Investigator
Professor
School of Human Evolution and Social Change
Arizona State University

Cynthia Claus, M.P.H. – Co-Investigator
Doctoral Student
School of Human Evolution and Social Change
Arizona State University

Purpose: Why is the study being done?

You are being asked to take part in this study because you are over 18 years of age, and reside in, or are a member of the Yavapai-Apache community.

The purpose of this study is to identify and describe the shared cultural knowledge and beliefs in the Yavapai-Apache Community about cancer. The information that is provided by community members could potentially contribute to the development of a more culturally responsive cancer prevention education program for the community.

Procedures: What is involved in the study?

If you agree to be in this study, you will be asked to do the following:

- 1) A face-to-face interview will be completed at a time that is convenient for your schedule at a quiet location that ensures your privacy and confidentiality. The interview will last about 1½ hours. You will be asked some questions about information you may know about cancer prevention, diagnosis and treatment. You may skip any questions you choose not to answer.
- 2) You will be asked to fill out a short questionnaire providing some general background information that will help in making sure that there is good representation of participants from the community.
- 3) A second face-to-face interview will be schedule to review the information you provided in the first interview to make sure that the information that was collected correctly states what you said and also will allow you to provide any information you may wish to add. The interview will last about one hour. It will be scheduled at a time that is convenient for your schedule and at a quiet location that ensures your privacy and confidentiality.

There will be approximately 25 individuals who will complete the face-to-face interviews. The interview sessions will be recorded on a digital recorder to ensure the accuracy of the information collected.

The information that is provided from the interviews will be used to develop a survey about cancer knowledge and beliefs that will be distributed to approximately 200 community members who will also volunteer to participate and complete the survey.

Potential Risks and Discomforts: What are the Risks of the Study?

There are no expected risks or discomforts to the participants should you decide to participate in the study. However, some of the questions may be of a personal or sensitive nature. You may choose to **not** answer any question you do not want to answer.

The information collected will be kept confidential and number codes will be used instead of names. All electronic/computer information will be password protected and all printed documentation will be kept in locked cabinets.

Potential Benefits: Are there any benefits to taking part in the study?

Although there may be no direct benefit to you by taking part in the study, it may help the researchers better understand shared knowledge and beliefs of the Yavapai-Apache community about cancer. This information could potentially help in the development of a more culturally responsive

cancer prevention education program for the Yavapai-Apache community, but this cannot be guaranteed.

The other possible benefit of your participation in the study is that it may also help in the way this kind of research is done in other tribal communities to create better ways to develop cancer prevention education.

Confidentiality: What about confidentiality?

All information obtained in this study is strictly confidential. Your name will not be kept in the files. Your name will be replaced with a code number.

Anyone who takes part in the study will not be identified in any of the results of this research study that may be used in reports, presentations, and publications. In any report we may publish, we will not include any information that will make it possible to identify any individual and will summarize the information in a combined way, without using any individual names or specific identification.

The records of this study will be kept private. The records will be kept in a locked file; any electronic records of the study on a computer will be protected by a password known only by the researchers; only the researchers of this study will have access to the information. Your name will not be kept in the files. Your name will be replaced with a code number. All interview information, surveys and digital recordings will be locked in a research filing cabinet and/or protected by a password on a computer that only the researchers would be able to use.

The interviews will be recorded on a digital recorder and transcribed. The recording is to make sure that all the important information is correctly written just as the participant states it. If you do not wish to be recorded, you may request that the recorder be turned off when you talk. The recording and written transcriptions will be destroyed by deleting the digital recording and shredding the documents when the study is completed. The only research members who will have access to the recordings and/or transcript documents are the Principal Investigator, Elizabeth Brandt, Ph.D. and the Co-Principal Investigator, Cynthia Claus, MPH.

Voluntary Nature of the Study: What are my rights as a participant?

Your decision to take part in this study is completely voluntary. And if you agree to participate now, you may choose not to answer certain questions, and you may drop out of the study at any time by letting the interviewer or researcher know that you do not wish to take part in the study any longer. Your decision whether or not to participate **will not** affect your current or future relations with the Arizona State University or with your health care provider, clinic or hospital. Your participation in this study is voluntary.

If you decide to withdraw at any time, we will ask you if you want any of the information you have provided up to that point to not be included and if you would like the audio recordings erased. We will fulfill your stated request.

Costs and Payments: What are the costs?

You will not be asked to pay any costs related to this research. We want your decision about taking part in the study to be absolutely voluntary. It is recognized that by your taking part in the study, it may cause some inconvenience to your regular schedule and responsibilities. In order to provide small compensation for your time and helping with this study, you will receive a \$25.00 gift card if both interviews are completed for your participation. This will be provided at the end of the second interview.

Contacts and Questions: Who do I call if I have questions or problems?

You may ask any questions you have about the research study or your participation in the study now, or if you have any questions later you may contact them at:

Elizabeth Brandt, Ph.D.
Arizona State University
School of Human Evolution and Social Change
P.O. Box 872402
Mail Code: 2402
Tempe, AZ 85287-2402
Phone: 480.965.5992
Betsy.Brandt@asu.edu

Cynthia Claus, M.P.H.
Arizona State University
School of Human Evolution and Social Change
P.O. Box 872402
Tempe, AZ 85287-2402
Phone: 602.618.3866
cclaus@asu.edu

If you have any questions or concerns about your rights as a participant in this research, or if you feel you have been placed at risk; you can contact the Chair of the Human Subjects Institutional Review board, through the ASU Office of Research Integrity and Assurance, at 480.965.6788.

This form explains the nature, demands, benefits and any risk of the project. By signing this form you agree knowingly to assume any risks involved. You may choose not to participate or to withdraw your consent

and discontinue participation at any time without penalty or loss of benefit. In signing this consent form, you are not waiving any legal claims, rights, or remedies.

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study.

You will be given (offered) a copy of this signed consent form.

Subject's Signature Printed Name Date

Witness (if applicable): Printed Name Date

INVESTIGATOR'S STATEMENT

"I certify that I have explained to the above individual the nature and purpose, the potential benefits and possible risks associated with participation in this research study, have answered any questions that have been raised, and have witnessed the above signature. These elements of Informed Consent conform to the Assurance given by Arizona State University to the Office for Human Research Protections to protect the rights of human subjects. I have provided (offered) the subject/participant a copy of this signed consent document."

Signature of Investigator _____ Date _____

APPENDIX E
SURVEY PARTICIPANT'S INFORMED CONSENT

CONSENT FORM

Title: The Shared Cultural Knowledge and Beliefs about Cancer In the Yavapai-Apache Community

Introduction

You are invited to be in a research study. The study is called “The Shared Cultural Knowledge and Beliefs about Cancer in the Yavapai-Apache Community.” The study has been reviewed and approved by the:

- the Yavapai-Apache Tribal Council
- Arizona State University, Office of Research Integrity and Assurance
- Dr. Peterson Zah, Special Advisor to the President, American Indian Initiatives, Arizona State University

Please take your time to make your decision. It is important that you read and understand several general principles that apply to all who take part in this study:

- a) Taking part in the study is entirely voluntary;
- b) You will receive no direct benefit from taking part in the study, but knowledge may be gained from your participation that may benefit others in your community;
- c) You may withdraw from the study at any time without it affecting your current or future relationship with Arizona State University or with your health care provider, clinic or hospital.

Please read this form and feel free to ask any questions about this study with the individuals who explain it to you.

The researchers of the study are:

Elizabeth Brandt, Ph.D. – Principal Investigator and Professor

School of Human Evolution and Social Change
Arizona State University

Cynthia Claus, M.P.H. – Co-Investigator

Doctoral Student
School of Human Evolution and Social Change
Arizona State University

Purpose: Why is the study being done?

You are being asked to take part in this study because you are over 18 years of age, and reside in, or are a member of the Yavapai-Apache community.

The purpose of this study is to identify and describe the shared cultural knowledge and beliefs in the Yavapai-Apache Community about cancer. The information that is provided by community members could potentially contribute to the development of a more culturally responsive cancer prevention education program for the community.

Procedures: What is involved in the study?

If you agree to be in this study, you will be asked to complete a survey that will:

- 1) ask questions about whether you agree or disagree about statements about cancer, and,
- 2) provide some general background information that will help in making sure that there is good representation of participants from the community.

There will be approximately 75 individuals who will complete the survey. The information that is provided from the surveys completed by community members could potentially contribute to the development of a more culturally responsive cancer prevention education program for the Yavapai-Apache community.

Potential Risks and Discomforts: What are the Risks of the Study?

There are no expected risks or discomforts to the participants should you decide to participate in the study. However, some of the questions may be of a personal or sensitive nature. You may choose **not** to answer any question you do not want to answer.

Potential Benefits: Are there any benefits to taking part in the study?

Although there may be no direct benefit to you by taking part in the study, it may help the researchers better understand shared knowledge and beliefs of the Yavapai-Apache community about cancer. This information could potentially help in the development of a more culturally responsive cancer prevention education program for the Yavapai-Apache community, but this cannot be guaranteed.

The other possible benefit of your participation in the study is that it may also help in the way this kind of research is done in other tribal communities to create better ways to develop cancer prevention education.

Confidentiality: What about confidentiality?

All information obtained in this study is strictly confidential. Your name will not be recorded and only code numbers will be assigned to the surveys. The signed consent will not be connected or identified with your completed survey.

Anyone who takes part in the study will not be identified in any of the results of this research study that may be used in reports, presentations, and publications. In any report we may publish, we will not include any information that will make it possible to identify any individual and will summarize the information in a combined way, without using any individual names or specific identification.

The records of this study will be kept private. The information collected will be kept confidential and number codes will be used instead of names. The records will be kept in a locked file; any electronic records of the study on a computer will be protected by a password known only by the researchers; only the researchers of this study will have access to the information. Your name will not be kept in the files.

Voluntary Nature of the Study: What are my rights as a participant?

Your decision to take part in this study is completely voluntary. And if you agree to participate now, you may choose not to answer certain questions, and you may drop out of the study at any time by letting researcher know that you do not wish to complete the survey.

Your decision whether or not to participate **will not** affect your current or future relations with the Arizona State University or with your health care provider, clinic or hospital. Your participation in this study is voluntary.

If you decide to withdraw at any time, we will ask you if want any of the information you have provided up to that point to not be included. We will fulfill your stated request.

Costs and Payments: What are the costs?

You will not be asked to pay any costs related to this research.

We want your decision to complete the survey to be absolutely voluntary. It is recognized that by your taking part in the study, it may cause some

inconvenience to your regular schedule and responsibilities. In order to provide small compensation for your time in completing the survey, you will receive a \$10.00 gift card. This will be provided when the survey has been completed.

Contacts and Questions: Who do I call if I have questions or problems?

You may ask any questions you have about the research study or your participation in the study now, or if you have any questions later you may contact them at:

Elizabeth Brandt, Ph.D.
Arizona State University
School of Human Evolution and
Social Change
P.O. Box 872402
Mail Code: 2402
Tempe, AZ 85287-2402
Phone: 480.965.5992 or 480-205-0477
Betsy.Brandt@asu.edu

Cynthia Claus, M.P.H.
Arizona State University
School of Human Evolution and
Social Change
P.O. Box 872402
Tempe, AZ 85287-2402
Phone: 602.618.3866
cclaus@asu.edu

If you have any questions or concerns about your rights as a participant in this research, or if you feel you have been placed at risk; you can contact the Chair of the Human Subjects Institutional Review board, through the ASU Office of Research Integrity and Assurance, at 480.965.6788.

This form explains the nature, demands, benefits and any risk of the project. By signing this form you agree knowingly to assume any risks involved. You may choose not to participate or to withdraw your consent and discontinue participation at any time without penalty or loss of benefit. In signing this consent form, you are not waiving any legal claims, rights, or remedies.

Signing this consent form indicates that you have read this consent form (or have had it read to you), that your questions have been answered to your satisfaction, and that you voluntarily agree to participate in this research study.

You will be given (offered) a copy of this signed consent form.

Subject's Signature Printed Name Date

Witness (if applicable): Printed Name Date

INVESTIGATOR'S STATEMENT

"I certify that I have explained to the above individual the nature and purpose, the potential benefits and possible risks associated with participation in this research study, have answered any questions that have been raised, and have witnessed the above signature. These elements of Informed Consent conform to the Assurance given by Arizona State University to the Office for Human Research Protections to protect the rights of human subjects. I have provided (offered) the subject/participant a copy of this signed consent document."

Signature of Investigator _____ Date _____

APPENDIX F

TELEPHONE OR FACE-TO-FACE OUTREACH RECRUITMENT SCRIPT

TELEPHONE or FACE-TO-FACE RECRUITMENT SCRIPT

I am contacting you to see if you might be interested in participating in a research study to identify and describe the shared cultural knowledge and beliefs in the Yavapai-Apache community about cancer.

I am (or “I am assisting”) Cynthia Claus, a graduate student under the direction of Professor Elizabeth Brandt in the School of Human Evolution and Social Change (SHESC) at Arizona State University, who will be conducting the study.

I am (assisting her in) recruiting individuals who are older than 18 years old and from the Yavapai-Apache community to participate in two interviews:

- the first interview will last about 1 ½ hours and will be scheduled at a convenient time for your schedule at a location that ensures your privacy and confidentiality,
- the second face-to-face interview will be scheduled to review the information you provided during the first interview to make sure that the information you provided is correctly stated and to also allow you to add any additional information you may wish to add. The interview will last one hour or less, and
- You will also be asked to fill out a short questionnaire providing some general background information that will help in making sure that there is a good representation of participants from the community.

The interviews will be recorded and transcribed. The recording is to make sure that all the important information is correctly written just as the participant states it. If you do not wish to be recorded, you may request

that the recorder be turned off when you talk. The recording and written transcriptions will be destroyed by deleting the recording and shredding the documents when the study is completed.

All information obtained in this study is strictly confidential. Your name will not be kept in the files. Your name will be replaced with a code number. Anyone who takes part in the study will not be identified in any of the results of this research study that may be used in reports, presentations, and publications. In any report that may be published, it will not include any information that will make it possible to identify any individual and will summarize the information in a combined way, without using any individual names or specific identification.

Although there may be no direct benefit to you by taking part in the study, it may help the researchers better understand shared knowledge and beliefs of the Yavapai-Apache community about cancer. This information could potentially help in the development of a more culturally responsive cancer prevention education program for the Yavapai-Apache community. The other possible benefit of your participation in the study is that it may also help in the way this kind of research is done in other tribal communities to create better ways to develop cancer prevention education. There are no foreseeable risks or discomforts to your participation.

Your participation in this study is voluntary. Everyone who completes both interviews and the short questionnaire will receive a \$25.00 gift card.

If you are interested in finding out more information about how you can participate, you can reach Ms. Claus at: 602.618.3866 or by e-mail at cclaus@asu.edu

APPENDIX G
KEY CONSULTANT'S INTERVIEW QUESTIONS

**Title: The Shared Cultural Knowledge and Beliefs about Cancer
in the Yavapai-Apache Community**

Yavapai-Apache Key Consultant Interview Questions:

Consent forms signed

(Bold font: Script for the interviewer.)

I appreciate your willingness to take the time to participate in this interview. As discussed earlier, the purpose of this study is to describe the shared knowledge and beliefs in the Yavapai-Apache Community regarding cancer. The information that is provided by community members could potentially contribute to the development of a more culturally responsive cancer prevention education program for the community.

Okay, let's begin:

1. What are some of the first thoughts that may come to a person's mind when they hear the word "cancer"? (*description*)
2. What are things that people may do that increase the possibility they will have cancer? (*cause*)
3. Would you explain your answer(s) about things that may increase the possibility of someone having cancer? (*cause*)
4. How could we learn more about these things that may increase the possibility of having cancer? (*cause*)
5. What do you think about when you hear someone talk about "prevention" when talking about cancer? (*prevention*)
6. What are some of the ways that people can keep themselves from getting cancer? (*prevention*)
7. Would you explain your answer(s) about the ways that people can keep themselves from getting cancer? (*prevention*)
8. How would we know that these ways work? (*prevention*)
9. How would we know that these ways do not work? (*prevention*)
10. What are ways people can find out if they have cancer? (*screening*)
11. What are some thoughts that come to mind when people talk about ways to "treat" cancer? (*treatment*)
12. What are some of the ways that are used to treat cancer? (*treatment*)
13. Would you describe the ways that cancer can be treated? (*treatment*)

14. What are some thoughts that come to mind when people talk about ways to make cancer go away permanently from a person's body? (prognosis)
15. What do you think about the word "cure" when people talk about cancer?
16. What types of cancer can be cured? (*prognosis*)
17. Would you explain your answer(s) about the types of cancer that can be cured? (*prognosis*)

18. What do you think about how a person is able to live once they have been told they have a diagnosis of cancer? (*prognosis*)
19. Why do you think some people are able to live once they have been told they have a diagnosis of cancer? (*prognosis*)
20. What do you think are things a person can do that would increase their chances of living with a diagnosis of cancer? (*prognosis*)

21. What has been your knowledge or experience of members of the community who have experienced cancer? (*experience*)
22. What has been your family's experience with cancer? (*experience*)
23. What has been your experience with cancer? (*experience*)

24. Is there anything else you would like to say? Anything we talked about that you would like to go back to?
25. Would you be interested in having more information about cancer given to you? (will provide information if asked either in pamphlet/booklets or at a community education meeting)

We have completed the interview. I want to thank you, (name), very much for taking the time to answer these questions. After I have been able to review the information you have provided, would it possible for me to contact you again so I can make sure I recorded all the information correctly? It will also give you some time to think about any other information you would like to share that you may think of after we've completed the interview today.

Would it be convenient for me to contact you by phone or e-mail?

Would you provide me with that contact information?

I would appreciate it if you could complete a short questionnaire with some background information to help us make sure we are including a good representation of the community.

(After completion of background questionnaire)

Thank you again for your time and effort. The information you have provided will help in developing a larger community-wide written survey that will be distributed to Yavapai-Apache tribal members to better understand their knowledge and beliefs about cancer.

APPENDIX H
PILE SORT THEMES

Themes	Item
PREVENTION	
	1 age
	2 avoid alcohol use
	3 breastfeeding
	4 chemicals
	5 diet
	6 drink a lot of water
	7 education
	8 exercise
	9 avoid exposure to the sun
	10 heredity
	11 sexual intercourse
	12 soda pop
	13 tobacco use
	14 Yavapai-Apache lifestyle
CAUSE	
	1 age
	2 alcohol use
	3 lack of breastfeeding
	4 cement plant
	5 chemicals
	6 diet
	7 downwinders (nuclear testing exposure)
	8 lack of drinking a lot of water
	9 lack of education
	10 lack of exercise
	11 exposure to the sun
	12 heredity
	13 mine/smelter
	14 sexual intercourse
	15 soda pop
	16 tobacco use
	17 lack of Yavapai-Apache lifestyle
TREATMENT	
	1 attitude
	2 check ups
	3 chemotherapy
	4 herbs/plants
	5 hospice
	6 medication
	7 prayer
	8 radiation
	9 spiritual belief
	10 surgery
	11 traditional ceremonies
	12 traditional practitioner (medicine man)

APPENDIX I
KEY CONSULTANT DEMOGRAPHIC SURVEY

**Please answer the questions to the best of your ability.
Please do not leave any blank answers.**

BACKGROUND INFORMATION:

A. Tribal Information:

1. Are you an enrolled member of the Yavapai-Apache Nation?

(circle one)

1 – Yes

2 - No

2. If yes, are you (circle one):

1 - Yavapai

2 - Apache

c) Both

3. If you are not an enrolled member of the Yavapai-Apache Nation are you enrolled in another tribe?

1 – Yes

2 – No

If yes, in what tribal community are you enrolled?

(Please list) _____

4. Do you live on the Yavapai-Apache reservation?

1 – Yes

2 – No

If yes, in which community do you live?

a) Camp Verde

c) Clarkdale

e) Tunlii

b) Middle Verde

d) Rimrock

If no, what is the name of the town you live in or live nearest to?

(Please list) _____

5. Have you ever moved away from the Yavapai-Apache community?

1 – Yes

2- No

If yes, how long were you away? _____

6. Have you recently moved back to the community?

1 – Yes

2- No

If yes, how long has it been since you returned? _____

7. What is the total amount of time you have lived/worked/ in the Yavapai-Apache community?
- a) 0 - 5 years
 - b) 6 – 10 years
 - c) 11 – 20 years
 - d) more than 20 years

B. Culture and Language

Some families have special activities or traditions that take place every year at particular times – such as holiday gatherings, special meals or giveaways, religious activities, healing ceremonies, or honoring powwows.

1. What are some of the special events, activities or traditions that take place in the Yavapai-Apache community?

2. How many of these special activities or traditions does your family take part in that are based on Yavapai-Apache/American Indian culture? (circle one)

1 - not at all 2 – a few 3 - some 4 - a lot

2. How many of these special activities or traditions does your family take part in that are **not** based in Yavapai-Apache/American Indian culture (circle one)

1 - not at all 2 – a few 3 - some 4 - a lot

3. What is your degree of American Indian heritage or tribe(s) you identify with? (Some examples are: 1/4, 3/8, 15/16, 4/4 or full.) Include ancestry in **ANY** tribe (for example, if you are 1/4 Apache and 1/4 Hopi):

<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>
<hr/>	<hr/>	<hr/>

4. Some people talk about living life in traditional ways. To what extent do you follow the Yavapai-Apache/American Indian way of life?

(circle one)

1 - not at all 2 – very little 3 - some 4 - a lot

5. Can you name a couple of these traditional ways?

6. To what extent do you follow the White-American way of life?

(circle one)

1 - not at all 2 – very little 3 - some 4 - a lot

7. Can you name a couple of White-American ways?

8. How important is it to you that you maintain your tribal identity?

(circle one)

1 – very important 2 – somewhat important 3 – not important

9. How important is it to you that you maintain your Tribe's values and practice? (circle one)

1 – very important 2 – somewhat important 3 – not important

10. How important is it to you that you maintain White-American values?

(circle one)

1 – very important 2 – somewhat important 3 – not important

11. How important is it to you that you maintain White-American practices? (circle one)

1 – very important 2 – somewhat important 3 – not important

12. This question asks about your religious and spiritual background.

What is your religious or spiritual background?

(circle all those that apply)

1 – Protestant (circle type)

a) non-denominational

b) denomination (name): _____

2 – Catholic

3 – Mormon

4 – Native American Church (NAC)

5 – Traditional Indian Beliefs

6 – None, no religion

7 - Other _____

13. To what extent are you and your family involved in spiritual or religious activities?
1 – very involved 2 – somewhat involved 3 – not involved
14. What is your tribal language? (circle all that apply)
1 - Yavapai 3 - Spanish
2 – Apache 4 - Other (name): _____
3 – Both 1 and 2
15. If your language is Yavapai, how well do you speak your tribal language? (**circle one**)
1 - I speak my tribal language very well
2 - I speak it moderately well
3 - I speak it a little, but not very well
4 - I don't speak my tribal language but understand some of it
5 – I don't speak my tribal language
16. If your language is Apache, how well do you speak your tribal language? (**circle one**)
1 - I speak my tribal language very well
2 - I speak it moderately well
3 - I speak it a little, but not very well
4 - I don't speak my tribal language but understand some of it
5 – I don't speak my tribal language
17. If your language is ("Other"- name) _____, how well do you speak your tribal language? (**circle one**)
1 - I speak my tribal language very well
2 - I speak it moderately well
3 - I speak it a little, but not very well
4 - I don't speak my tribal language but understand some of it
5 – I don't speak my tribal language

C. Demographic Information

1. What was your age on your last birthday? _____
2. What is your gender?
1 – male 2 – female
3. What is the highest grade you attended in school?
a) Some high school f) Associates degree
b) GED g) Bachelor's degree
c) High school graduate h) Graduate school
d) Trade school/technical degree i) Other _____
e) Some college

4. What is your current marital status?
- | | |
|----------------------------|-----------------------|
| a) Never married | c) Divorced/separated |
| b) Married/live as married | d) Widowed |
5. What is your current employment status?
- | | |
|---------------|----------------------------|
| a) Employed | e) Disabled/Unable to work |
| b) Unemployed | f) Student |
| c) Homemaker | g) Other _____ |
| d) Retired | |
6. How many people live with you in your house?
- | | |
|---------|-----------------|
| a) None | d) 3 |
| b) 1 | e) 4 |
| c) 2 | f) Other: _____ |
7. How many children (yours or your grandchildren) under 16 years old live with you in your house?
- | | |
|---------|--------------|
| a) None | d) 3 |
| b) 1 | e) 4 or more |
| c) 2 | |
6. What is the total income before taxes of all persons living in your house in calendar year 2010? (in other words, all those who share/live in your house.)
- | | |
|------------------------|------------------------|
| a) Less than \$10,000 | e) \$40,000 - \$49,999 |
| b) \$10,000 - \$19,999 | f) \$50,000 – 59,999 |
| c) \$20,000 – \$29,999 | g) \$60,000 – or more |
| d) \$30,000 - \$39,999 | h) don't know |

APPENDIX J
COMMUNITY SURVEY

COMMUNITY SURVEY
The Shared Cultural Knowledge and Beliefs about Cancer
in the Yavapai-Apache Community

Thank you for your willingness to take the time to complete this survey. The information that is provided by your participation could potentially help in the development of a culturally responsive cancer prevention education program for the community.

Please answer the questions to the best of your ability. There are no “right or wrong” answers. We are interested in your opinions.

Please do not leave any blank answers.

Description

1) Do you think of death or dying when you hear the word “cancer”?

1 – Yes 2 – No

2) Is cancer a deadly disease?

1 – Yes 2 – No

3) Is cancer something to be feared?

1 – Yes 2 – No

4) Is cancer contagious?

1 – Yes 2 – No

5) Is cancer curable?

1 – Yes 2 – No

6) Is cancer a common disease among American Indians/
Native Americans?

1 – Yes 2 – No

7) Is cancer preventable?

1 – Yes 2 – No

8) Does cancer include the uncontrolled growth of cells in the body?

1 – Yes 2 – No

Risk/Cause

- 1) Are elders at greater risk for developing cancer than younger people?
1 – Yes 2 – No
- 2) Do chemicals in the environment increase the chances of getting cancer?
1 – Yes 2 – No
- 3) Does being a “downwinder” (exposure to nuclear fallout) increase the risk of developing cancer?
1 – Yes 2 – No
- 4) Do people who have lived or worked near a mine or smelter have a greater risk of developing cancer?
1 – Yes 2 – No
- 5) Is cancer hereditary?
1 – Yes 2 – No
- 6) Does alcohol consumption increase the risk for cancer?
1 – Yes 2 – No
- 7) Do the types of food we eat increase the risk of cancer?
1 – Yes 2 – No
- 8) Does smoking cigarettes increase a person’s chance of getting cancer?
1 – Yes 2 – No
- 9) Does using chew tobacco increase the risk of a person getting cancer?
1 – Yes 2 – No

10) Do you think that being in a place with cigarette smoke over a long period of time will increase a person's chances of getting cancer?

1 – Yes 2 – No

Prevention

1) Does breastfeeding reduce a woman's chance of getting cancer?

1 – Yes 2 – No

2) Is cancer preventable?

1 – Yes 2 – No

3) Does education or knowledge about cancer increase an individuals' ability to prevent cancer?

1 – Yes 2 – No

4) Does regular exercise help prevent cancer?

1 – Yes 2 – No

5) Does eating a nutritious diet help in preventing a person from getting cancer?

1 – Yes 2 – No

6) Can cancer be detected early with tests?

1 – Yes 2 – No

7) Can regular checkups with a doctor help in preventing cancer?

1 – Yes 2 – No

Treatment

1) Can cancer be treated with herbs and plants?

1 – Yes 2 – No

2) Can chemotherapy treat cancer?

1 – Yes 2 – No

3) Can cancer be treated by a traditional practitioner/medicine man?

1 – Yes 2 – No

4) Can cancer be treated with traditional ceremonies?

1 – Yes 2 – No

5) Can radiation treat cancer?

1 – Yes 2 – No

6) Can surgery treat cancer?

1 – Yes 2 – No

7) Does chemotherapy cause loss of hair?

1 – Yes 2 – No

8) Does radiation cause fatigue?

1 – Yes 2 – No

Remission/Cure

1) Does cancer eventually come back even after treatment has been given?

1 – Yes 2 – No

2) Does cancer ever go completely away after treatment?

1 – Yes 2 – No

3) Can cancer be cured?

1 – Yes 2 – No

4) Can prayers cure cancer?

1 – Yes 2 – No

5) Can miracles cure cancer?

1 – Yes 2 – No

6) Is cancer in “remission” when it stops spreading in the body?

1 – Yes 2 – No

7) Does “remission” mean a person doesn’t have cancer anymore?

1 – Yes 2 – No

Living with Diagnosis

1) Is a person’s attitude important in how they live their life?

1 – Yes 2 – No

2) Do people with cancer who have a positive attitude live longer with a cancer diagnosis than those who do not?

1 – Yes 2 – No

3) Do people who have been told that they have cancer but deny it as a true diagnosis cope better with cancer (or live longer) than those who accept a cancer diagnosis as true?

1 – Yes 2 – No

4) Do people with cancer who eat a healthy diet increase the length of their life more than people who do not?

1 – Yes 2 – No

5) Is a person’s faith in God important in how they live their life?

1 – Yes 2 – No

6) Do people with a stronger faith in God cope with cancer (or live longer) than those who do not?

1 – Yes 2 – No

- 7) Is prayer an important influence in how people live their life?
1 – Yes 2 – No
- 8) Do people with cancer who pray regularly cope with their cancer better (or live longer) than people who do not pray?
1 – Yes 2 – No
- 9) Does reading the Bible affect how people live their life?
1 – Yes 2 – No
- 10) Do people who read the Bible regularly cope with their cancer better (or live longer) than people who do not?
1 – Yes 2 – No
- 11) Is spirituality important in how people live their life?
1 – Yes 2 – No
- 12) Do people who believe spirituality is important in their lives cope with their cancer better (or live longer) than people who do not?
1 – Yes 2 – No
- 13) Is family support important in how people live their life?
1 – Yes 2 – No
- 14) Do people who have the support from family cope with their cancer better (or live longer) than people who do not?
1 – Yes 2 – No
- 15) Are traditional/cultural beliefs important in how people live their life?
1 – Yes 2 – No
- 16) Do people who practice traditional/cultural beliefs cope with their cancer better (or live longer) than people who do not?
1 – Yes 2 – No

17) Is participation in traditional ceremonies important in how people live their life?

1 – Yes 2 – No

18) Do people who regularly participate in traditional ceremonies cope with their cancer better (or live longer) than people who do not?

1 – Yes 2 – No

19) Is treatment by a traditional practitioner/medicine man important in how people live their life?

1 – Yes 2 – No

20) Do people who receive their treatment from a traditional practitioner/medicine cope with their cancer better (or live longer) than people who do not?

1 – Yes 2 – No

Information

1) Do you use the internet to get most of your information about cancer?

1 – Yes 2 – No

2) Does your doctor provide the information you need about cancer?

1 – Yes 2 – No

3) Do you think there enough information provided about cancer in the Yavapai-Apache community?

1 – Yes 2 – No

4) Do you think that brochures and pamphlets about cancer provide information that you use?

1 – Yes 2 – No

- 5) Do you think that the tribal newspaper would be a good way to provide educational information to the community about cancer?
- 1 – Yes 2 – No
- 6) Do you think that community events about cancer (walks, runs, presentations, etc.) have helped you become more aware about the prevention of cancer?
- 1 – Yes 2 – No
- 7) Would you attend community presentations to learn more about how you can prevent cancer?
- 1 – Yes 2 – No

Screening Information

- 8) Have you heard about any medical tests that can detect cancer?
- 1 – Yes 2 – No
- 9) Have you every completed a cancer screening test at a clinic or at your doctor's office?
- 1 – Yes 2 – No
- 10) Have you ever had a medical test for colon cancer (colonoscopy)?
- 1 – Yes 2 – No
- 11) If you are female, have you ever had a mammogram?
- 1 – Yes 2 – No
- 12) If you are a female, have you ever completed a breast self-exam?
- 1 – Yes 2 – No
- 13) If you are female, do you complete regular monthly breast self-exams?
- 1 – Yes 2 – No
- 14) If you are a male, have you ever had a test for prostate cancer?
- 1 – Yes 2 – No

15) Do you know someone who has been diagnosed with cancer?

1 – Yes 2 – No

If yes, what type of cancer?

How long did they live with the diagnosis?

16) Has a member of your family ever been diagnosed with cancer?

1 – Yes 2 – No

If yes, what type of cancer?

How long did they live with the diagnosis?

17) Have you ever been diagnosed with cancer?

1 – Yes 2 – No

If yes, what type of cancer?

How long have you been diagnosed?

Demographics

A. Tribal Information:

1) Are you an enrolled member of the Yavapai-Apache Nation?
(circle one)

1 – Yes 2 – No

2) Do you live on the Yavapai-Apache reservation?

1 – Yes 2 – No

3. What is your degree of American Indian tribe(s) or blood quantum you identify with? (Some examples are: 1/4, 3/8, 15/16, 4/4 or full.) Include ancestry in **ANY** tribe (for example, if you are 1/4 Apache and 1/4 Hopi):

4. Some people talk about living life in traditional ways. To what extent do you follow the Yavapai-Apache/American Indian way of life?
(circle one)

- 1 - not at all 2 – very little 3 - some 4 - a lot

5. Can you name a couple of these traditional ways?

6. To what extent do you follow the White-American way of life?
(circle one)

- 1 - not at all 2 – very little 3 - some 4 - a lot

7. Can you name a couple of White-American ways?

8. How important is it to you that you maintain your tribal identity?
(circle one)

- 1 – very important 2 – somewhat important 3 – not important

9. How important is it to you that you maintain your Tribe’s values and practice? **(circle one)**

- 1 – very important 2 – somewhat important 3 – not important

10. How important is it to you that you maintain White-American values?
(circle one)

- 1 – very important 2 – somewhat important 3 – not important

11. How important is it to you that you maintain White-American practices? **(circle one)**

1 – very important 2 – somewhat important 3 – not important

12. What is your tribal language? **(circle all that apply)**

1 - Yavapai

3 - Spanish

2 – Apache

4 - Other (name): _____

3 – Both 1 and 2

13. **If your language is Yavapai**, how well do you speak your tribal language? **(circle one)**

1 - I speak my tribal language very well

2 - I speak it moderately well

3 - I speak it a little, but not very well

4 - I don't speak my tribal language but understand some of it

5 – I don't speak my tribal language

14. **If your language is Apache**, how well do you speak your tribal language? **(circle one)**

1 - I speak my tribal language very well

2 - I speak it moderately well

3 - I speak it a little, but not very well

4 - I don't speak my tribal language but understand some of it

5 – I don't speak my tribal language

15. **If your language is ("Other"- name) _____**, how well do you speak your tribal language? **(circle one)**

1 - I speak my tribal language very well

2 - I speak it moderately well

3 - I speak it a little, but not very well

4 - I don't speak my tribal language but understand some of it

5 – I don't speak my tribal language

C. Religious and Spiritual Information

1. What is your religious or spiritual background?

(circle all those that apply)

- | | |
|---------------------------------------|----------------------------------|
| 1 – Protestant (<u>circle type</u>) | 3 – LDS (Mormon) |
| a) non-denominational | 4 – Native American Church (NAC) |
| b) denomination (<u>name</u>): | 5 – Traditional Indian Beliefs |
| _____ | 6 – None, no religion |
| 2 – Catholic | 7 - Other _____ |

2. To what extent are you and your family involved in spiritual or religious activities?

- 1 – very involved 2 – somewhat involved 3 – not involved

D. Medical Services Information

1. Where do you go **most often** to see a doctor?

- Yavapai-Apache Medical Center
- Phoenix Indian Medical Center (PIMC)
- Other local private provider (example: Cottonwood, Sedona)

2. When you go to a clinic or doctor's office, what do you use to provide for the payment of the services you receive (circle all that apply):

- IHS
- Private/tribal insurance
- AHCCCS (Arizona Health Care Cost Containment System)
- Medicare
- Self-pay

E. Demographic Information

1. What was your age on your last birthday? _____

2. What is your gender?

- 1 – male 2 – female

ID # _____

3. What is the highest grade you attended in school?

- | | |
|----------------------------------|----------------------|
| a) Some high school | f) Associates degree |
| b) GED | g) Bachelor's degree |
| c) High school graduate | h) Graduate school |
| d) Trade school/technical degree | i) Other _____ |
| e) Some college | |

4. What is your current marital status?

- | | |
|----------------------------|-----------------------|
| a) Never married | c) Divorced/separated |
| b) Married/live as married | d) Widowed |

5. What is your current employment status?

- | | |
|---------------|----------------------------|
| a) Employed | e) Disabled/Unable to work |
| b) Unemployed | f) Student |
| c) Homemaker | g) Other _____ |
| d) Retired | |

7. How many people live with you in your house?

- | | |
|---------|-----------------|
| a) None | d) 3 |
| b) 1 | e) 4 |
| c) 2 | f) Other: _____ |

8. How many children (yours or your grandchildren) under 16 years old live with you in your house?

- | | |
|---------|--------------|
| a) None | d) 3 |
| b) 1 | e) 4 or more |
| c) 2 | |

9. What is the total income before taxes of all persons living in your house in calendar year 2010? (in other words, all those who share/live in your house.)

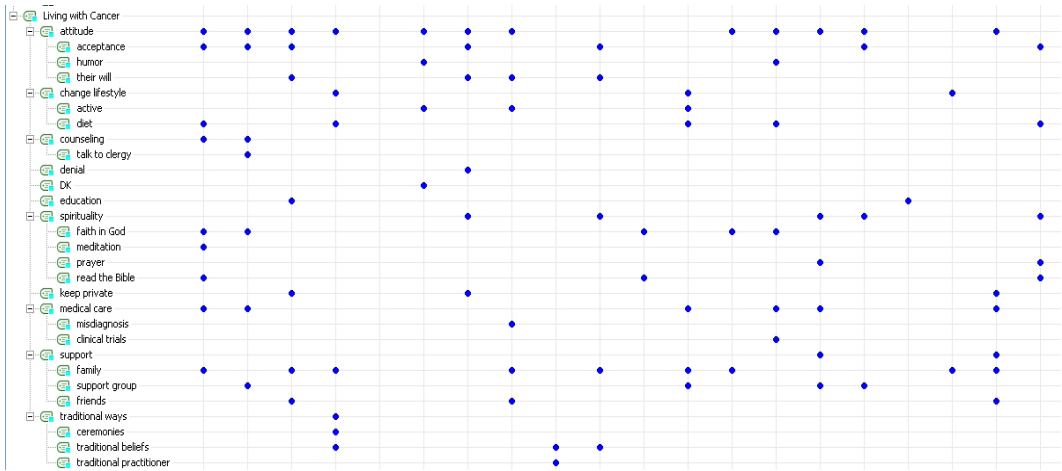
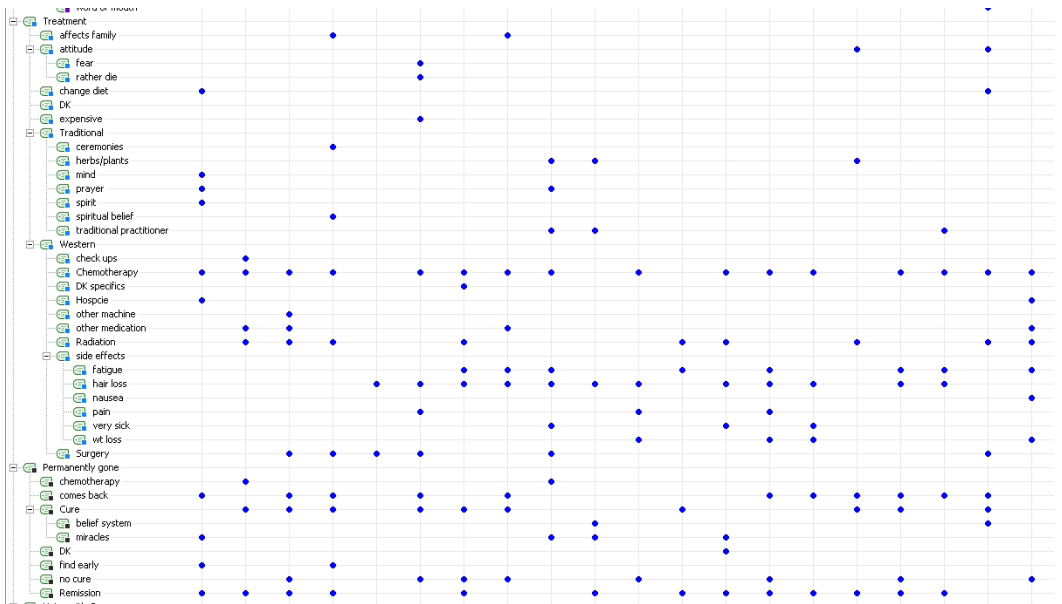
- | | |
|------------------------|------------------------|
| a) Less than \$10,000 | e) \$40,000 - \$49,999 |
| b) \$10,000 - \$19,999 | f) \$50,000 - 59,999 |
| c) \$20,000 - \$29,999 | g) \$60,000 - or more |
| d) \$30,000 - \$39,999 | h) don't know |

APPENDIX K

CODE MATRIX FOR ETHNOGRAPHIC INTERVIEWS

Code System	Ink 101	Ink 102	Ink 103	Ink 104	Ink 105	Ink 106	Ink 107	Ink 108	Ink 109	Ink 110	Ink 111	Ink 112	Ink 113	Ink 114	Ink 115	Ink 116	Ink 117	Ink 118	Ink 119	Ink 120	
Ca Description																					
contagious																					
death/dying																					
different kinds																					
don't talk about it																					
don't understand																					
ds																					
feared																					
illness																					
in control																					
just happens																					
keep to ourselves																					
life changing																					
not contagious																					
not curable																					
not fatal																					
not preventable																					
not scary anymore																					
part of aging																					
passing/receiving the doc																					
preventable																					
sadness/sorrow																					
scary/dread																					
treatment																					
unaware																					
uncontrollable growth/s...																					
Increase Ca																					
Age																					
Dr																					
drug use																					
Environmental																					
environment part																					
chemicals																					
water																					
food/drink/water/...																					
contaminants																					
indicator																					
clean bottles																					
cleaner/disposal																					
recycle waste																					
heredity																					
Lifestyle																					
abusing alcohol																					
fat																					
lack of exercise																					
social interaction																					
soda pop																					
tobacco use																					
second-hand smoke																					
transfusion																					
Trauma																					
Prevention																					
breastfeeding																					
can't prevent																					
Dr																					
Educ. info																					

Code System	Ink 101	Ink 102	Ink 103	Ink 104	Ink 105	Ink 106	Ink 107	Ink 108	Ink 109	Ink 110	Ink 111	Ink 112	Ink 113	Ink 114	Ink 115	Ink 116	Ink 117	Ink 118	Ink 119	Ink 120	
Lifestyle																					
drink a lot of water																					
exercise																					
exposure to sun																					
healthy diet																					
not abusing alcohol																					
not using tobacco																					
YA traditional lifestyle																					
Medical																					
screenings																					
medical checkups																					
HPV Vacc																					
Info About Ca																					
Detect Dz																					
MRI																					
biopsy																					
screening																					
BSA																					
colonoscopy																					
mammogram																					
pap																					
see doctor																					
symptoms																					
General Information																					
community events																					
community groups																					
conferences																					
community walk...																					
internet																					
medical source																					
nurse																					
doctor																					
not provided in com...																					
presentations																					
printed media																					
newspapers																					
books																					
magazines																					
training																					
Tribal programs																					
tribal newspaper																					
home visits																					
medical center																					
TV																					
word of mouth																					



APPENDIX L
PERCENT OF KEY CONSULTANTS MENTIONING AN ITEM AS
CHARACTERISTIC OF CANCER

Category	Item	Total N=20	% KCs
PREVENT CANCER			
Educ Info		7	35
Lifestyle			
	drink a lot of water	2	10
	exercise	8	40
	exposure to sun	3	15
	healthy diet	8	40
	not abusing alcohol	2	10
	not using tobacco	7	35
	YA traditional lifestyle	2	10
Breastfeeding		1	5
INCREASE/CAUSE CANCER			
Age		3	15
Environmental			
	cement plant	3	15
	chemicals	12	60
	Downwinders	12	60
	mine/smelter	5	25
	plastic bottles	1	5
Heredity		4	20
Lifestyle			
	tobacco use	11	55
	food	7	35
	lack of exercise	3	15
	abusing alcohol	2	10
	soda pop	2	10
	sexual intercourse	1	5
Drug use		1	5
Transfusion		1	5
Trauma		1	5
WAYS TO TREAT CANCER			
Attitude/spirit		5	25
Change diet		2	10
Traditional			
	traditional practitioner	3	15
	herbs/plants	3	15
	prayer	2	10
	spiritual belief	2	10
	ceremonies	1	5
Western			
	chemotherapy	16	80
	radiation	9	45
	surgery	6	30
	other medication	4	20
	hospice	2	10
	check ups	1	5
	other machine	1	5

APPENDIX M
PERCENT OF KEY CONSULTANTS MENTIONING AN ITEM AS
DESCRIPTIVE OF CANCER

Category	Item	Total N=20	% KCs
CANCER DESCRIPTION			
	death/dying	11	55
	fear	10	50
	uncontrollable growth/spreads fast	8	40
	just happens	7	35
	not curable	6	30
	keep to themselves	5	25
	dz	4	20
	life changing	4	20
	illness	3	15
	not preventable	2	10
	silent/hidden	2	10
	contagious	1	5
	not in AI	1	5
	different kinds	1	5
	don't talk about it	1	5
	don't understand	1	5
	in denial	1	5
	not contagious	1	5
	not scary anymore	1	5
	part of aging	1	5
	poisoning/rotting the blood	1	5
	preventable	1	5
	sadness/sorrow	1	5
	treatment	1	5
	unaware	1	5
PERMANENTLY GONE			
	Remission	13	65
	comes back	11	55
	Cure	10	50
	belief system	2	10
	miracles	4	20
	no cure	8	40
	chemotherapy	2	10
	find early	2	10
	DK	1	5

Category	Item	Total N=20	% KCs
LIVING WITH CANCER			
attitude		12	60
	acceptance	7	35
	humor	2	10
	their will	4	20
support		2	10
	counseling	4	20
	family	9	45
	support group	4	20
	friends	3	15
	talk to clergy	1	5
spirituality		5	25
	faith in God	5	25
	meditation	1	5
	prayer	2	10
	read the Bible	3	15
change lifestyle		3	15
	diet	5	25
	active	3	15
medical care		6	30
	misdiagnosis	1	5
	clinical trials	1	5
traditional ways		1	5
	ceremonies	1	5
	traditional beliefs	3	15
	traditional practitioner	1	5
keep private		3	15
denial		1	5
DK		1	5

APPENDIX N
DEMOGRAPHIC CHARACTERISTICS OF COMMUNITY SURVEY
PARTICIPANTS

SURVEY DEMOGRAPHICS		
GENDER		
Male	22	
Female	52	
Total	74	
AVERAGE AGE		
Male	44	
Female	42	
Total	45	
EDUCATION		
some HS	11	14%
GED	7	9%
HS grad	10	12%
Trade	5	6%
Some college	26	32%
AA	11	14%
Bachelor's	6	7%
Grad School	3	4%
Other	2	2%
MARITAL STATUS		
never married	31	41%
married	23	31%
divorced	15	20%
widowed	6	8%
EMPLOYMENT		
employed	48	64%
unemployed	13	17%
home	5	7%
retired	2	3%
disabled	5	7%
student	1	1%
other	1	1%
LIVING IN HOUSEHOLD		
1	7	9%
2	9	12%
3	13	18%
4	16	21%
5	13	18%
6>	14	22%
INCOME		
>\$10,000	12	16%
\$10,00-\$19,999	6	8%
\$20,00-\$29,999	20	27%
\$30,000-\$39,000	4	5%
\$40,000-\$49,999	6	8%
\$50,000-\$59,999	11	15%
\$60,000>	10	14%
DK	5	7%

APPENDIX O

TRIBAL RESOLUTION IN SUPPORT OF THE DISSERTATION SUBMISSION
TO THE ASU LIBRARY THROUGH PROQUEST/UMI PUBLISHING

RESOLUTION NO. 87-11
OF THE GOVERNING BODY OF THE
YAVAPAI-APACHE NATION

A Resolution Approving the Electronic Submission of a Doctoral Dissertation to the
ASU Library for Publication Through UMI/ProQuest –
The Shared Cultural Knowledge and Beliefs About Cancer
in the Yavapai-Apache Community

- WHEREAS:** The Yavapai-Apache Tribal Council (“Council”) is authorized to represent the Yavapai-Apache Nation (“Nation”) and act on all matters that concern the health and welfare of the Nation, and to make decisions not inconsistent with or contrary to the Constitution of the Yavapai-Apache Nation; and
- WHEREAS:** The Council is the legislative body of the Nation authorized to enact laws, ordinances, and resolutions incidental to the exercise of legislative powers as provided by Article V(v) of the Nation’s Constitution; and
- WHEREAS:** Cancer is the second leading cause of deaths among American Indians and Alaska Natives over the age of 45 according to the Indian Health Services; and
- WHEREAS:** The Arizona Department of Health Services (“ADHS”) Cancer Registry in 2005 indicates that compared to Arizona’s average age-adjusted cancer mortality rate from 1999-2001 (173.7/100,000), Yavapai County has the second highest death rate due to cancer (196.4/100,000) in the state; and
- WHEREAS:** A research project has been completed applying cultural consensus theory and a combined approach utilizing qualitative and quantitative research techniques to identify and describe the Yavapai-Apache Nation community’s cultural knowledge and beliefs regarding cancer; and
- WHEREAS:** The research project has been reviewed by a Community Advisory Committee composed of three community members who actively participated during the implementation of the project by: 1) reviewing and finalizing the final research proposal, 2) reviewing and approving updates throughout the progress of the project, 3) providing input of needed changes or amendments, 4) reviewing and inputting the final analysis and results, and 5) reviewing and approving the final report for presentations and dissertation publication; and

WHEREAS: The researcher worked in partnership with the Community Advisory Committee to have a clear understanding of culturally sensitive issues and to ensure that the dignity and privacy of all tribal members was maintained; and

WHEREAS: An informed consent was administered that explained the study in detail, participants were allowed to withdraw anytime without any penalty, 20 key individuals in the community were interviewed on a voluntary basis regarding their knowledge and beliefs about cancer; and

WHEREAS: A Community survey was developed and distributed to 75 community members, 21 years of age and older, an informed consent was administered that explained the study in detail, completion of the survey was on a voluntary basis regarding their knowledge and beliefs about cancer, and participants were allowed to withdraw anytime without any penalty; and

WHEREAS: All precautions were taken to maintain the highest levels of confidentiality of everyone who consented to participate in this study; and

WHEREAS: The final results and report of the completed research study has been written as a doctoral dissertation by Cynthia Claus, MPH; and

WHEREAS: The title of the doctoral dissertation is “The Shared Cultural Knowledge and Beliefs about Cancer in the Yavapai-Apache Community”; and

WHEREAS: The Council finds it in the best interest of the Nation to authorize Cynthia Claus, MPH to submit the doctoral dissertation titled, “The Shared Cultural Knowledge and Beliefs about Cancer in the Yavapai-Apache Community” to the ASU Library for Publication through UMI/ProQuest.

NOW THEREFORE BE IT RESOLVED that the Yavapai-Apache Tribal Council, in Council assembled, at which a quorum is present, approves and authorizes Cynthia Claus, MPH, of Arizona State University, School of Human Evolution and Social Change, to submit the doctoral dissertation titled, “The Shared Cultural Knowledge and Beliefs about Cancer in the Yavapai-Apache Community” (*attached as Exhibit A*), to the ASU Library for Publication through UMI/ProQuest.

BE IT FINALLY RESOLVED that the Chairman, and Vice-Chairman, or either of them, are hereby authorized and approved to take such further action as deemed necessary to carry out the purposes and intent of this Resolution.

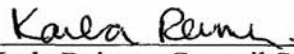
CERTIFICATION

I hereby certify that the foregoing resolution was adopted by an affirmative vote of the Tribal Council, with a quorum in attendance, presented for approval on May 5 2011, by a vote of 8 7 in favor, 1 opposed and 6 abstaining, pursuant to the authority contained under the Constitution of the Yavapai-Apache Nation as cited above.

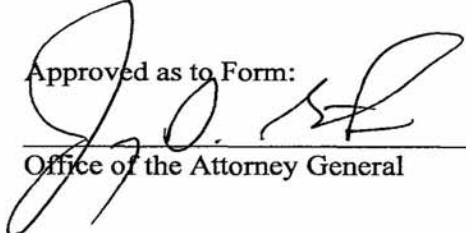


David Kwail, Chairman

ATTEST:



Karla Reimer, Council Secretary

Approved as to Form:


Office of the Attorney General