

ORIGINAL ARTICLE

“EATING FOR OUTSIDERS”: CANCER CAUSATION DISCOURSE AMONG THE IÑUPIAT OF ARCTIC ALASKA

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ABSTRACT

Objectives. Cancer is the leading cause of death among Alaska Natives. Although cancer mortality rates are widely studied, as well as high-risk behaviours in relation to site-specific tumors, little is known about Alaska Native understandings of cancer. This study explores how Iñupiat living in northwest Alaska conceptualize the etiology, transmission and prevention of cancer.

Study Design. Long-term ethnographic research.

Methods. Qualitative research was conducted in northwest Alaska over the course of 30 months, including 8 months accompanying an Iñupiaq family on their seasonal rounds to hunting and fishing camps. In addition, open-ended interviews were conducted with 50 Iñupiaq men and women, and the life histories of 3 Iñupiaq healers were recorded.

Results. Iñupiat spoke of cancer as a germ-induced condition that emerged from the “outside.” Routes of infection include the ingestion of contaminated food and water, as well as inhalation or injection of outside agents. “Bad-blood” was considered a precursor to, and product of, cancer. Iñupiaq discourse about cancer prevention focused on consuming foods that strengthened the blood, including meat harvested from the country. Educational efforts that focused on lowering risk by eating diets low in meat and fat and high in fruit and vegetables were rejected as an assault from outsiders on their hunting way of life.

Conclusions. The development of meaningful cancer prevention and early detection programs must be sensitive not only to cultural conceptions of disease but also to relations of power in which recommendations and policies are constituted and asserted. (*Int J Circumpolar Health* 2008; 67(4):374-383)

Keywords: Iñupiat, Alaska Native, cancer, health, public health policy

INTRODUCTION

Cancer is the leading cause of death among Alaska Natives (1). Among the population of roughly 107,000 Iñupiat, Aleut, Athabascan and Tlingit-Haida (2), cancer is the leading cause of death among women and the third leading cause of death among men (1). The northern “epidemic” of cancer is noteworthy not only because of the 12% increase in cancer mortality rates from 1979–1998 (1) but also because mortality from certain cancer types is higher in Alaska Natives than in other Americans (3–6).

A great deal of research has been conducted on the epidemiologic profile of cancer among Alaska Natives (7,8), as well as assessments of “high-risk” behaviours associated with site-specific tumors (9). However, ethnographic research (10) on how Alaska Natives conceive of the etiology, transmission and prevention of cancer has largely been neglected. This article highlights 4 broad themes in Iñupiaq ethnomedical understandings of cancer and discusses the importance of these idioms for developing meaningful and effective cancer intervention programs.

Numerous social scientific studies have documented local knowledge and beliefs regarding cancer (11–13). All too often, this body of work uses survey research to compare Indigenous beliefs about etiology to biomedical understandings of causation and risk. This approach leaves little opportunity to uncover idioms that exist outside of Euro-American categories of risk, accountability and symptomology (14). Moreover, culture-specific idioms of disease are often glossed as “misconceptions,” “lay misperceptions” or “inadequate” understandings of Western scientific truths,

ultimately portraying culture as a barrier to the early detection, treatment and prevention of cancer (15–17).

Anthropologists have long advocated for using methodologies that allow one to elicit locally defined world views, explanatory models and culturally specific diagnostic criteria (18–20). With an ethnographic approach, such as participant observation and open-ended interviews, one may begin to appreciate how local knowledge relates to help-seeking practice in a given cultural setting. In addition, by understanding ethnomedical systems in specific politico-economic contexts, one may avoid the medicalization or pathologizing of human misery arising from oppression and inequality. And attention to the clinical encounter in which explanatory models are negotiated and contested may invite practitioners to reflect on how their own practices are informed by cultural convention and systems of power. Ultimately, the ability to achieve a truly “culturally competent” clinical practice is predicated on a holistic understanding of locally experienced realities, not as mere variations of biomedical formulations, or as cognitive constructions isolated from lived reality, but as articulations of meaning in larger political and social systems (21,22).

MATERIAL AND METHODS

Research setting

This research was conducted in the Northwest Arctic Borough, a region encompassing 36,000 square miles above the Arctic Circle. Eleven villages reside within this borough, with Kotzebue (population 3,082) serving as the regional hub (2). The 1992 discovery of an

abandoned federal radioactive waste dump (23,24), a by-product of the Atomic Energy Commission program known as Project Chariot, reignited local theories that exposure to toxic waste was adversely affecting health (25). Public health officials downplayed this discovery and continued to assert the importance of healthy life-styles and personal choices in cancer prevention.

Cancer education campaigns were implemented at the regional level by a physician from the lower 48 who managed the Health Education Department of the regional non-profit health corporation known as the Maniilaq Association. Radio announcements, cooking classes and a monthly publication titled "Good Health: It's Your Choice" (26) promoted the message that cancer prevention begins with exercise, a balanced diet low in fats and animal products (27) and abstinence from smoking (28). Iñupiat were also exposed to health information from a variety of other sources, including clinical encounters, news in the popular press, television shows, videos and, of course, the illness experiences of friends and family members.

A demographic profile of Kotzebue residents, the town where the majority of the participants in this study lived at the time of this research, is as follows: The median age of Kotzebue residents is 26 years, compared to 35 years old in the U.S. population (2). The per capita income in Kotzebue in 1999 was U.S.\$18,289, with a median family income of U.S.\$58,068 (2). Substantial economic disparity exists between families in this region, and the percentage of residents living in poverty ranges from 6% to 37% (2). Thirty percent of Kotzebue residents over 16 years old are unemployed.

The extent to which Kotzebue residents were engaged in harvesting food from the land is estimated by the Survey of Living Conditions in the Arctic (29) as follows: 82% pick berries, 77% fish, 71% preserve meat or fish, 50% hunt caribou, moose or sheep, 29% hunt waterfowl, 37% hunt seal or ugruk, 24% gather eggs, 5% hunt walrus and 3% trap. Involvement in subsistence activities is an important point of reference, since enduring engagements with the land shape sensibilities about health and well-being in important ways.

Overview of methods

This research is based on 30 months of ethnographic research conducted in north-west Alaska between 1993 and 1996. Qualitative research methodologies were utilized, including 17 months of participant observation in the regional hub of Kotzebue, as well as 8 months accompanying an Iñupiaq family on their seasonal rounds to hunting and fishing camps. In order to elicit a variety of Iñupiaq perspectives, the author spent brief periods of time (1–3 weeks) in the communities of Evik, Seshaulik, Point Hope, Ambler, Kiana and Shungnak. In addition, semi-structured interviews were conducted with 50 Iñupiaq men and women, and the life histories of 3 healers who had extensive experience treating cancer were recorded and transcribed. Lastly, the author interviewed 15 hospital and public health personnel at the local health centre, attended health and environment-related conferences outside of the region and conducted archival research on health and healing at the University of Alaska Anchorage and at the University of Alaska Fairbanks.

Informed consent

Approval to conduct this research was obtained from the Maniilaq Association, the Kotzebue Elders Council and the Institutional Review Board of the University of Wisconsin-Madison. Permission to interview individual Northwest Arctic Borough residents was achieved through either written or verbal consent.

Participant observation

Upon arriving in Kotzebue in August 1993, the author began working as a counsellor and “live in” at the only domestic violence shelter in the Northwest Arctic Borough. She remained employed in this position for 9 months and engaged in a range of tasks including one-on-one counselling, assistance with applications for restraining orders, facilitation of anti-violence workshops, supervising children and cooking and baking for the elderly. In this capacity of “social worker,” a role that followed her throughout her fieldwork, the author developed a rapport with clients, their extended families and the Maniilaq Association staff. The author also became actively involved in community life, including attending Friends Church services, basketball games, birthday parties and baby showers, as well as boating, camping and picking wild berries during the late summer months.

After a year of residence in Kotzebue, the author moved across Kotzebue Sound to an isolated “camp” and accompanied an Iñupiaq family on their seasonal rounds from hunting to fishing camps. This provided a rare opportunity to participate in a range of subsistence activities and speak with Iñupiat about disease processes while harvesting caribou, fish, seals and walrus. Four members of the author’s host family served as “key informants” in this

research and provided multiple interviews over the course of this project. In addition, a semi-structured interview guide was developed, and 50 additional villagers were interviewed, predominantly in the town of Kotzebue.

Initially the interview guide was characterized by broad, open-ended questions in an effort to understand the various (historical, moral, social) contexts in which Iñupiat made sense of cancer. Informants were also asked about their conceptions of the cause, cure and prevention of cancer. Additional topics of conversation included the history of cancer in the region and concerns with environmental pollution, both emotionally charged topics that appeared time and again during months of prior fieldwork. The interview guide was altered periodically, and became more focused over time, in an effort to gain more specific information regarding key themes in the data.

Iñupiat were recruited to participate in the interview phase of this project in one of several ways. After months of residence in the region, the author approached co-workers, friends and acquaintances with a request to be interviewed. (No one declined to participate, although some were hesitant to have their interviews tape recorded.) Others were identified using a snowball sampling technique in which informants were asked to identify friends or relatives who may be willing to be interviewed. The author also approached individuals who were well known for their engagement in regional politics or had family members who were diagnosed with cancer. Roughly half of the participants were strangers to the author at the time of the first interview, and 40% of the participants were interviewed on more than one occasion. Of the 50 participants, 34 were women and 16 were men. The median age of

the informants was approximately 45 years old, with an age range from 18 to 85.

Approximately 15 of the 50 interviews were tape recorded, and hand written notes were taken during all the interviews. All interviews were conducted in English, and a bilingual instructor with the Northwest Arctic Borough School District provided assistance in translating Iñupiaq words and phrases that appeared in their narratives.

The analysis was guided by grounded theory (30). All interviews, field notes and field journal entries were coded for key words and phrases. Then a master file of key words was created, and analytic memos were generated that included an excerpt from the interview or field journal entry and location of the excerpt (e.g., under key word “cancer” appears hundreds of entries, such as “his body is poisoned [July1995–26]).” Upon returning from the field, photocopies of all data corresponding to an entry under a key word were compiled in a folder. Additional memos were created that identified prominent themes as well as revealed variations in perspectives. No pre-packaged software analysis system was utilized in this analysis, and the analysis was conducted solely by the author.

RESULTS

Etiology

Iñupiaq informants, both young and old alike, spoke of cancer as an infectious agent that emerged from the “outside.” Considered yet another disease that was introduced by white people and for which they have no immunity, cancer was loathed for its virulence much like measles and influenza that killed three-

fourths of the Iñupiat population in the early 1900s (31). A middle-aged Iñupiaq hunter commented, “*When you get down to it, the people that came to live with us introduced a lot of this stuff like TB and cancer. Cancer was not heard of back then.*” Another informant in his mid-60s stated, “*Maybe the Indigenous people are going through a phase like we did with tuberculosis. Alaskan Natives, when I was a boy, were all expiring from TB. That’s what killed my mother. They had no immune system for it. A while back I was caribou hunting with two or three other guys, we all agreed about this. Cancer is an outside disease that was introduced in one way or another.*”

Middle-aged and elderly informants, unlike the informants in their 20s and 30s, often related cancer to their ancestors’ experiences with tuberculosis. Iñupiaq elders, for instance, expressed resentment about losing close family members to the “blood-spitting” disease and felt a similar sense of vulnerability and helplessness in preventing cancer’s spread. In her emotional testimony, an Iñupiaq healer in her 50s explained, “*This cancer is a white man’s disease. Hundreds of people died of tuberculosis when I was a child. I had one brother die. These epidemics are terrible, frightening for us! And now there is cancer. We have no immunity to these diseases.*”

Although Iñupiaq informants attributed cancer’s spread to a number of different living agents, including worms, bugs, flies, bacteria and worms, the most common idiom through which Iñupiat described the transmission of cancer was “germs.” As a politically prominent Iñupiaq man in his 50s once remarked, “*As the cancer germ enters, we can’t fight against it.*” Several informants described cancer as moving between people who lived

in close proximity, although most informants described cancer germs as entering the body through contaminated food and water and weakening the blood.

Transmission

For many Iñupiat, blood is intimately involved in the cancerous process. Initially started by a “germ” that creates an *immak* (puss) sore that “cannot be cured,” the *immak* spreads (*samittsaq*) - through the body and poisons the blood. A range of “outside” influences or foreign agents are capable of weakening the blood and creating puss, including chlorine in town water, radiation in the land, preservatives and pesticides in food and chemicals in cigarettes.

Although ingestion was considered the most likely entry point of these cancer-causing agents, Iñupiat also spoke of alternative routes of infection such as inhalation and injection. For instance, several informants speculated that tumors were introduced into the body by shots and medicines that they received as a child at the local clinic.

Cancer was associated with *augiitchuq* (bad-blood), a condition of the circulation marked by “slow,” “weak,” “bad,” “thin” or “watery” blood. Iñupiat consistently spoke of bad-blood both as a precursor to, as well as a product of, cancer. For instance, one teenager who lived at camp noted, “*Sometimes that bad-blood runs in generations. Cancer is like that, it happens the same way. If the circulation is not flowing, it’s going to rot in there.*” Similarly, a woman in her 30s attributed her bout with breast cancer to previous abuse by a boyfriend and noted that the blood behind the bruise was unable to flow properly. Another informant who worked as a cleaner

for the local government described the role of blood in cancer etiology in this way, “*Cancer starts when the blood cells start to decay and die, because the blood cells can’t take nutrients from the blood. Something is stopping the healthy cells from absorbing. Cancer is a poison killing the [blood] cells.*”

The intermarriage of whites and Iñupiat was cited as creating a weakness in the bloodline to deal with foreign substances. An Iñupiaq man linked cancer to interracial marriages in this way, “*If you mix two full bloods, one Native and one Caucasian, it weakens the immune system. When races mix, the outcome is a person susceptible to many diseases. The chain is weakened.*” A hunter in his late 20s also echoed this sentiment by emphasizing how intermarriage “weakens” the bloodline of children: “*I’m not blaming you, but people come from out there, and a lot in their blood system is dead. Most of their glands. So the body can’t take care of itself. And then it should pass through the bloodline that way. Just look how the caribou are getting weaker from the reindeer.*”

Prevention

Iñupiaq discourse on cancer prevention focused on avoiding both the consumption of contaminated foods and exposure to outside agents. Contamination was a broad term used to index both store-bought foods, riddled with pesticides and preservatives, and environmental pollution such as radioactive waste. Iñupiaq informants over 60 years old often emphasized that their bodies had originally adjusted to the marine and land mammals in their midst, and to stray too far from their “diet of birth” was to invite illness. One great-grandfather implored the younger generation to quit “eating for

outsiders” with their taste for sodas, pizza and chips. He also criticized the youth’s dependence on microwaves: *“These microwaves are making us act like white people.”* Another man in his late-60s chided his own children for “dividing their families” by eating country foods and feeding their children “outside” foods.

Reputed to be watery, lifeless, without blood or heat, and riddled with additives and preservatives, store-bought foods were considered to weaken the blood. As one Iñupiaq man in his 60s explained, *“Cancer is a problem mainly because of change in diet. You can see it in the stores. Do they sell niqipaq (country foods) there? No. People don’t read the ingredients in a can of soup. All kinds of preservatives. The body can’t adjust to the changes real quick. It weakens bodies, weakens the immune system...Twinkies, you could set on a piece of wood and come back ten years later – it would still be the same. No wonder we’re poisoning ourselves.”*

Concerns with environmental pollution, however, made eating country foods a highly charged experience in the mid-1990s for the young and old alike (25). An informant in his late 20s who hunted for his parents on a regular basis explained the current dilemma with strengthening the blood in this way, *“The blood from meat makes your own blood real strong, real healthy. The old people told us that cooking meat takes the power out of it. It’s better to eat the meat raw. But the animals are too sick to eat them raw now.”*

Despite concerns with environmental pollution, many hunters expressed confidence in their ability to “protect” their families from “radiation sickness” by avoiding animals that showed signs of illness, especially those that

were skinny, weak or infested with worms. Cooking the radiation “out” of meat was also discussed as a strategy to deal with environmental pollution. As one middle aged hunter noted, *“I’m not worried about pollution. When an animal has something wrong with it, we can tell one shot. Sometimes they look so bad we won’t let the dogs eat it. But it’s hard to tell when an animal eats sickly food, until pollution gets its way through the animal. That’s the tricky part. We just cook it harder. Our family can’t eat animals where you see the pollution’s already got it.”* An elderly great-grandmother also emphasized the importance of carefully inspecting meat from the land for signs of contamination when she noted, *“Some meats have little white puss. When a carcass has too much puss, we don’t eat it. It may carry germs. We watch our meats and fish. Young people don’t know these things.”*

Expert knowledge

Iñupiaq theories and Western public health doctrine converged on the notion that food was integral to longevity, but cancer prevention campaigns that focused on diets low in animal fat and meat (27) and high in fruits and vegetables (32) were met with antagonism, especially by those who “lived off the land.” This dietary prescription for health struck some villagers as another intensified assault by Euro-Americans on their hunting way of life. Like Greenpeace and other environmental organizations that launched anti-hunting campaigns in the Far North, public health recommendations touting the benefits of store-bought foods (fruits, vegetables and low-fat meats) registered as an anti-Native agenda aimed at hunting. Disgusted over a cancer prevention announcement on the radio, the author’s host father quipped,

“These outsiders are blaming Eskimo foods too much. We are meat-eaters. Our body has memory for these foods. Let outsiders eat grass if they want to!”

Iñupiat also tended to distrust “expert knowledge” that contradicted conventional wisdom on how to survive Arctic winters. In opposition to the recommendation to “reduce your risk” of cancer by consuming more fruits and vegetables (that were often only available from the grocery store at high prices), one informant remarked: “Our Native food keeps us healthy. We are used to eating meat and fish and seal oil. The old people tell us that food will let us survive. If we just ate vegetables and water, we couldn’t survive out there. That food doesn’t stay in our insides long enough to keep us warm and healthy. It would just go right through us.” The ideal anti-cancer diet for outsiders was considered a prescription for death by Iñupiat, as one hunter in his 60s noted, “If I ate like that I wouldn’t even last a month. You could just bury me six feet under.”

DISCUSSION

In the midst of rising cancer mortality rates among Alaskan Natives, cancer prevention efforts seemed to be met with skepticism and distrust by Iñupiat. They were out of touch with Iñupiaq sensibilities about achieving health and well-being and were considered by many to be ideologically, rather than scientifically, driven. The model for healthy citizenship promoted by outsiders was viewed by some residents as a way to move Iñupiat off the land and into the grocery store, reinforcing what is considered to be an age-old colonial script

of making Inuit educated, money-carrying, apple-eating citizens of America. In short, Iñupiat interpreted public health assessments and recommendations within, not outside, a 200-year history of Iñupiaq–white relations.

Clearly Native oversight and control of services, as exists with the regional non-profit health corporations in Alaska, does not inevitably lead to the delivery of culturally meaningful services. This unfortunate situation may be attributed in part to the hiring of non-Native mid-level managers to direct health education and behaviour modification programs. All too often, these professionals move up from the lower 48 and have no appreciation for Iñupiaq culture or day-to-day Arctic realities, making it necessary, as Dixon et al. states, “to define more clearly the cultural values of the people they serve” (33).

Public health officials, health educators and clinicians should attempt to understand the cultural assumptions embedded in their own health models and services. The success of disease prevention campaigns is ultimately tied to anti-essentialist health promoting strategies that resonate with local communities. In northwest Alaska, this would require reframing dietary recommendations, highlighting particular foods as strengthening the blood and promoting circulation, acknowledging the limits of a discourse of “life-style choices” in communities that largely view cancer as an affliction and appreciating the extent to which the history of epidemics has shaped Iñupiat conceptions of disease causation and transmission.

Historical memories of epidemics are still on the forefront of Iñupiaq minds and have profoundly shaped a moral commentary about immunity, invasion and outsiders. Iñupiat do

not share, for instance, the Western epidemiologic distinction between “infectious” and “chronic” diseases and tend to view contemporary health conditions, including cancer, as germ-induced. In addition, some Iñupiat find it ironic that Euro-Americans were so sickly at the turn of the century that their diseases nearly devastated many Inuit communities, and now their offspring are “experts” on Iñupiat health and longevity. This irony makes some Iñupiat bristle at being told what to eat and how to live by outsiders. This is to say that “risk assessments” are always interpreted within culturally constituted spheres of power and history, and these interpretations are integral to the success or failure of health education campaigns.

There are several limitations to this study. Despite the author’s extensive travel in the Northwest Arctic Borough, this research was predominantly conducted in the Kotzebue region and does not represent the views of residents from surrounding villages. Moreover, the analysis of the data was conducted solely by the author. Further research is needed to determine the extent to which a colonial critique of public health and cancer prevention campaigns may differ among men and women and the younger and older generations.

Conclusions

Long-term ethnographic research on cancer suggests that Iñupiat view cancer as a product of complex colonial circumstances not of their making. Cancer is considered the most recent infectious disease unleashed by white people, but not the last. “Next thing you know,” an informant noted, “we will be catching AIDS from you guys.” Moreover, Iñupiat were especially sensitive to dietary recommendations

that restrict meat and fat, as they were interpreted in part as evidence of white opposition to hunting of seal, ugruk and whale. The development of meaningful cancer prevention and early detection programs in Indigenous communities must be sensitive not only to cultural conceptions of disease but also to relations of power in which recommendations and policies are constituted and asserted.

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