

# Gathering Information to Develop Palliative Care Programs for Alaska's Aboriginal Peoples

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**Abstract** / Over an eight-year period, the authors conducted focus groups in six Alaska Aboriginal communities. They sought information about traditional ways of caring for the dying, current values and preferences surrounding death, the kind of support caregivers need, and how a palliative care program could assist families caring for loved ones in the community. Focus groups are a standard qualitative research tool for gathering information when a new program or service is planned. However, for Alaska's Aboriginal people living in remote settings, the standard focus group design is not useful. That design was modified to reflect cultural norms and communication methods while adhering to standards of qualitative research. Communities selected represented different groups of Alaska's Indigenous people; 84 Aboriginal elders participated. Culturally modified focus groups yielded rich and useful information about historical and traditional practices surrounding death. Participants also vocalized expectations and concerns regarding their own eventual deaths. The process of conducting six different focus groups throughout Alaska yielded valuable information about community engagement in Aboriginal communities.

**Résumé** / Au cours d'une période de 8 ans, les auteures ont organisé la tenue de groupes ciblés de discussion dans six communautés autochtones en Alaska. Elles ont recueilli auprès de ces communautés de l'information portant sur leur façon traditionnelle de s'occuper des mourants, sur leurs valeurs communes, sur leurs préférences entourant la mort, sur la forme d'aide dont les soignants ont besoin et enfin sur la façon de concevoir un programme de soins palliatifs qui pourrait aider les familles et la communauté à s'occuper d'un de leurs membres. Les groupes de discussion sont un instrument de recherche standard lorsqu'il s'agit de recueillir de l'information pour la planification d'un nouveau service ou la mise en place d'un nouveau programme. Cependant, cet outil traditionnel de recherche n'était pas adapté aux besoins des groupes autochtones vivant dans les régions éloignées de l'Alaska. Les auteures ont donc dû le modifier afin qu'il reflète les normes culturelles et les méthodes de communication tout en se conformant aux standards de la recherche qualitative. Les communautés choisies pour ces rencontres étaient représentatives de différents

groupes autochtones de l'Alaska et comprenaient également 84 Anciens. Les groupes de discussion dont le modèle avait été modifié pour s'adapter à la culture autochtone ont permis de recueillir de l'information riche et utile quant aux coutumes historiques et traditionnelles entourant la mort. Les participants ont par ailleurs exprimé ouvertement leurs propres craintes et appréhensions concernant leur mort. Tout le processus entourant la tenue de ces groupes de discussions en Alaska a révélé à quel point l'engagement de toute la communauté chez les groupes autochtones était important.

## INTRODUCTION

Alaska's diverse Aboriginal population is generally grouped into categories based on cultural and linguistic factors (1). Like Indigenous peoples elsewhere, Natives in Alaska thrived for thousands of years by living off the land and sea and by creating social structures and belief systems that sustained them over time. Distinct cultural/linguistic groups originally resided in different geographical areas of Alaska. Cultural and linguistic differences can be traced to the type of resources available in these diverse regions. Six groups of Aboriginal people were included in this project: Tlingit/Haida, Yup'ik Eskimo, Inupiaq, Athabascan, Aleut, and Alutiiq/Sugpiaq.

Palliative care programs that provide an option for chronically ill patients to die at home or close to home are available in most communities throughout the United States and Canada. However, in Alaska's small, remote villages, it is difficult to provide palliative care that combines modern medicine with traditional ways. Alaska Native people often die alone in hospitals and nursing homes hundreds of miles from home. In earlier times, they died in the small villages where they had lived most of their lives, surrounded by family and friends.

Dr. John Simpson, discussing the care Barrow Eskimos gave to their elderly and sick, says:

"They not only gave them food and clothing, sharing with them every comfort they possess, but on the longest and most fatiguing journeys made provision for easy conveyance." Simpson further noted that in one camp of 14 families, a crippled old man and a helpless blind woman were both well cared for. Murdoch describes a local chief as "a feeble, bowed, tottering old man, very deaf and almost blind, but obviously still respected." Several travellers have noted that children, in particular, were concerned about the comfort of elders (2, p. 84).

The arrival of diseases like smallpox and influenza, along with Western medicine, diminished Aboriginal people's faith in their ability to care for each other with traditional remedies and healers in home communities (2). As Christianity spread through Alaska, traditional Native healers and spiritual leaders began to lose their stature and influence. As Robert J. Clark notes, "The way the missionaries told it, shamanism was no good. The Native people marveled [at] what the white people knew about treating new illnesses...the 'magic bullets' and other medicines. As the Native people gained respect for this new strength and power, they converted to Christianity and turned away from the traditional healers" (3, p. 3).

In 1998-2000, the Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care program awarded a grant to a tribal health organization in southwestern Alaska to develop a program to allow elders to remain at home as they neared the end of life. Part of the project was to gather information to develop a culturally relevant palliative care program and educational materials for families, volunteers, and medical staff.

The authors sought information about traditional ways of caring for the dying, current values and preferences surrounding death, the kind of support caregivers need, and how a palliative care program could assist families caring for loved ones in the community. When possible, the authors also gathered information from younger caregivers looking after a family member at home. The review of the literature focused on traditional cultural and historical practices surrounding illness, death, and caregiving in Alaska Native communities; the cross-cultural provision of palliative care; focus groups; and adaptations to accommodate cultural norms and communication patterns. The importance of relationships is addressed in the Method section.

Many Aboriginal practices and beliefs are passed on orally, but a review of the anthropological literature covered: traditional practices related to death and dying (1, 4), illness, and health care

(2, 5); funerary practices (6, 7); stories conveyed by village elders about medicine men, and the perspective on life and death in Alaska Native cultures as documented in school oral history programs and interviews (3, 8-10); and more recent accounts of family members' deaths (11, 12). The literature search yielded little information about culturally relevant interventions for end-of-life care.

In her work in American Indian communities, Kitzes indicates that while discussions about advance directives and impending death may not be acceptable, families have been able to explain what care they desire for the dying person. This includes having the dying person remain with family members in the home community (13, 14). Crawley emphasizes the need to collect more information about ethnic diversity in palliative care to ensure cultural sensitivity and competency in palliative medicine (15). The Palliative Care Council of South Australia has established multi-cultural guidelines reflecting the need to set aside one's own beliefs and seek to understand those of the other person (16). This is also confirmed in discussions of "cultural humility," an approach aimed at diminishing stereotypes that is "flexible and humble enough to assess anew the cultural dimensions of the experiences of each patient" (17, p. 119). These sources and the authors' experience in the field provided the foundation for the research.

Focus group research creates a permissive environment that nurtures differing points of view and facilitates interactive discussion (18, 19). Standard focus group practice involves groups of 7 to 10 people who have similar characteristics but do not know each other. Their meetings are conducted in a relaxed environment; the discussion is carefully planned and covers specified topics. The value of focus groups over individual interviews or surveys is that through them more knowledge is gained, due to the interaction and open discussion of participants facilitated by the probing of a skilled moderator.

Krueger indicates that focus groups are especially helpful when insights, perceptions, and detailed experience sharing are more important to the research than quantitative data, such as when researchers want to gather information about long-held traditions among Indigenous people (18). Marshall and Rossman report that listening to others express their opinions and understandings helps group members to express their own (19). Morgan explains that focus groups are useful when the researchers' need to record individual experiences is more important than their need to gather opinions (20).

Krueger states, "it is essential that researchers understand the culture and traditions" of a group when conducting cross-cultural focus groups (18, p. 216). In discussing the importance of relationships, Edwards and Egbert-Edwards (21) suggest that newcomers need to proceed slowly with American Indian and Alaska Native peoples; they need to identify problems clearly, follow through with commitments, and involve participants in the decision-making process. The authors indicate that regardless of the ethnic background of the newcomer, American Indian and Alaska Native peoples will assess his or her expertise and commitment prior to developing a relationship. Anthropologist Rosalie Wax "emphasized the importance of the researcher's initial contacts with members of the society or group chosen for study. The reciprocal relationship between host and field-worker enables the latter to avoid foolish, insulting, and potentially dangerous behaviour, to make valuable contacts, and to understand the acceptance and repayment of obligations" (19, p. 79).

Modifications necessary in focus groups conducted with different ethnic groups include careful selection of a moderator and sanctioning of the study by influential local people (18). Further modifications are highlighted in an article about conducting focus groups cross-culturally with Native Americans (22). Tom-Orme speaks about the importance of storytelling and allowing periods of silence and points to the need among those working with Indigenous Americans for translators who are older and experienced in the nuances of the traditional language (5).

## METHOD

In 1998, an Alaska Native advisory committee was brought together by the regional tribal health corporation in southwestern Alaska to help design a culturally appropriate palliative care program. The committee selected the name Helping Hands Program (23), and it discussed a wide range of topics — from memories about sick and dying relatives to more recent observations about people with life-limiting illnesses. Committee members used what they learned at their meetings to develop a list of questions for three focus group communities in the southwest with populations of between 100 and 700. These communities were highly dependent on the traditional lifestyle of hunting, fishing, and gathering. Thirty-four elders participated in the focus groups, which were conducted by DeCourtney and Branch.

Six years later, with the support of a National Cancer Institute (NCI) grant, the authors convened additional focus groups to gather informa-

tion to develop statewide palliative education programs. They selected Aboriginal communities outside southwestern Alaska to ensure that all the major cultural groups in the state had the opportunity to participate. These included an Inupiaq village on the north coast near the Canadian border, a Sugpiaq community on the south-central coast, a Tlingit/Haida city in the southeast, and an Athabascan community in the Alaska interior.

Two of the communities were similar in size to the southwestern Alaska communities and also depended on a traditional lifestyle. A southeastern Alaska urban community of 9,000 with a large Aboriginal population was added to the study to help determine any effects that environment might have on perceived needs for palliative care. This community had a much larger non-Aboriginal population, and its residents did not rely as much on a traditional lifestyle for sustenance.

The authors completed three of these visits. The visit to the Athabascan village was rescheduled several times due to a series of deaths in the community; it was cancelled when the time frame for conducting focus groups ended. A meeting in another village along the Aleutian Chain scheduled for another purpose provided additional information. Focus groups in these three communities added 50 participants to the study. Morgan (a Yup'ik Eskimo) joined DeCourtney and Branch for the second set of focus groups.

Through conversations with health organization board members, village council members, and senior service workers, the authors secured endorsement and support to travel to the communities and meet with elders. Village contact people helped the authors select the meeting times and locations, find appropriate translators, and decide what food to bring. Meetings were held in community buildings familiar to all residents. The focus groups were scheduled to last two to four hours, ensuring that participants had ample time to speak and participate in storytelling and that there could be respectful pauses. The authors brought enough food so that everyone could enjoy some at the meeting and participants could take leftovers home with them, along with some small gifts. These particular modifications reflected the cumulative experience of the authors in providing services and visiting with elders and others in rural Alaska villages over several years.

In small, remote communities, everyone knows one another. Historically, survival depended on communal support — hunters provided elders with meat, and food was shared. The authors therefore used the self-selection method to form the focus groups rather than sampling. Self-selection followed the cultural norm: all elders were invited.

Defining “elder” was left up to the community. Due to their common history and experience, elders, often linked by blood, marriage, or inter-family adoption, encouraged each other to share stories and assisted with translation.

Because of the time lapse between the two sets of focus groups, findings from the first set resulted in study design modification. Instead of sending flyers for a community to post in advance, the authors sent a letter to the tribal council describing the study and requesting permission to meet with elders and other community members. Follow-up calls ensured that the project was understood. Overnight stays in each community were scheduled, and food recommendations were obtained (the authors were told to bring dried seaweed, salmon strips, candy, pastries, and fresh fruit). The list of questions was slightly modified to accommodate the statewide organization sponsoring the research. The same moderator and co-moderator led the discussions. Each community was distinct, though members of all six shared a desire to remain at home as the end of life neared.

From experience working in these communities, the authors knew that they would have to be prepared for unanticipated changes of plan. For example, plans were in place to travel to one community, but the day before the scheduled meeting an airplane carrying two local elders crashed. All crew members and passengers died. The focus group trip was postponed. It would have been disrespectful to proceed on the heels of this tragedy.

It was important to remain flexible when dealing with the five small communities, as unexpected events could easily have altered the time and location of meetings. Aboriginal people in remote communities do not live by the clock. Their lives are ruled by the weather, geographic limitations, the movement of caribou herds, and fishing cycles.

None of the meetings started at the scheduled time — they began up to two hours later. In one community, the location was decided after the study team had arrived and possible meeting places had been discussed by local residents on the VHF radio.

People came to meetings by truck, all-terrain vehicle, and (in winter) snow machine. Adult children brought their parents. Depending on the size of the village and whether or not there was a road, a van might collect elders and bring them to a meeting. Elders would greet each other and catch up on local news. Eventually, everyone would sit down to enjoy the food and listen to the visitors. Branch, who works with elders, acted as primary moderator, while DeCourtney and Morgan provided support. There was generally one translator,

with additional translation provided by group members. Often an elder would tell a story that did not seem to relate to the question under discussion. However, as the story evolved, the message would become clear.

Defined moderator and co-moderator roles kept the discussion flowing (18). All sessions were recorded; two were videotaped. The researchers mingled with participants before meetings started and observed participants before, during, and after meetings.

## FOCUS GROUPS 2000-02

The first set of three focus groups (2000-02) was located in the southwestern Alaska villages where DeCourtney and Branch worked at tribal health and social service agencies. Village residents represented three Alaska Aboriginal groups: Yup'ik Eskimo, Aleut, and Athabascan. The villages are accessible only by aircraft. The lifestyle is primarily subsistence; hunting, fishing, and berry gathering bring in a large part of the food supply. The authors selected communities based on their familiarity with the inhabitants and with an eye to representing culture differences. Villages in which a home death had occurred during the previous two years received special consideration. Thirty-four elders participated in the first three focus groups.

The first focus group included very traditional elders who shared a history of caring for family members. A daughter noted, “When it was my mother-in-law’s time, I went upriver to be with her. When she could no longer drink, I dipped a feather in water to wet her lips.” The second focus group was part of a larger community gathering of elders and youths. One participant shared information about a recent death and how it was managed to encourage other participants to talk about their own experiences. Focus group participants included widows who had cared for their husbands at home. The next day, the tribal administrator said, “That was so good for those women. It was the first time they have talked about caring for their husbands.” The meeting of the third village focus group included a lunch. Participants declined to discuss sensitive issues such as death and dying, although they had recently experienced elder deaths. A visit to the local clinic yielded no further information.

Due to weather concerns, DeCourtney and Branch decided not to remain in the first community overnight, but Branch stayed on to attend to other business. She made informal visits to elders who had participated in the focus group and gathered critical information for the palliative care program design that had not been shared during

the meeting. Thereafter, the authors decided that they would remain in the villages overnight whenever possible to visit with residents and community leaders and collect valuable information not obtained during focus group meetings.

After completing each of the first three focus groups, the researchers transcribed and analyzed their notes and taped conversations. Findings from the first set of focus groups provided valuable information for the development of the Helping Hands Program and educational materials (23). These materials included: a storybook in which a respected tribal council elder answers his wife's questions about what changes are needed in the village to help a dying elder remain at home; a brochure for volunteers describing traditional ways of helping; and a brochure describing how the program integrates traditional ways and contemporary medicine.

When Helping Hands Program nurses had difficulty explaining how to use the Wong-Baker FACES Pain Rating Scale (24) to the wife of an ill elder ("He doesn't ever look like that"), the scale was adapted to better represent facial expressions of this stoic population so that symptoms could be accurately relayed by telephone to the nurses (23).

### FOCUS GROUPS 2006-08

A second set of focus groups was organized in Aboriginal communities throughout Alaska in order to gather information that reflected cultures other than those of southwestern Alaska. These communities included two small ones and a larger, more urban one. When the authors landed in the first small community, they looked around the tidy village. There was a strong sense of community there, but also a feeling of sadness due to a number of recent deaths. The tribal council was working to help residents understand how to prevent chronic disease through healthy living. Several speakers were scheduled to visit the village in the coming months. The authors had arranged to arrive a day before the meeting and stay for a day after it so that they could visit people. Unlike in the other villages, where Native dialects were dominant, English was the primary language here.

It was too difficult to set up visits with individual elders in the larger community, so the authors modified the format by adding two focus groups and meetings with staff of the Aboriginal hospital and a volunteer visiting and respite group. Obtaining a list of elders from community contacts, Morgan called each one with a personal invitation to attend a focus group meeting. The main focus group had lunch at a restaurant instead of sharing food in a community building.

Smaller focus group meetings were held in the evening at the national park cultural centre and the Pioneer Home (an assisted-living facility for seniors). Mixed findings came from this community. DeCourtney met an elder on the airplane who said, "Lots of elders don't want to die in the hospital because they don't want all the staff looking at them"; a hospital staff member said, "Elders like to die here because it is so nice." The elder declined to attend the meeting. Culturally, this community was very different from the others.

The last community was located far above the Arctic Circle. Although it was June and the sun shone almost 24 hours a day, people still wore winter parkas. This community was very welcoming and had a system of caring for people near the end of life that didn't overburden family members and local health providers. The meeting was conducted primarily in Inupiaq and translated into English by a local elder.

### RESULTS

Culturally modified focus groups yielded rich and useful information about historical and traditional practices surrounding death among Alaska's Aboriginal peoples. Participants expressed concerns regarding their own deaths; they also described what kind of help they might need as caregivers and how a palliative care program might benefit them. Reflections on each of these topics could benefit other researchers and providers of palliative care services.

#### Traditional Practices of Caring for the Dying

"We would take care of each other. There were no hospitals."

A speaker in the first village expressed a sentiment common to all of the groups: "Long time ago, we never sent elders away. We take care of them — no reason to send them away." Traditionally, families took care of their elders. It is seen as an obligation and a source of pride and joy for both the giver and the receiver of care. The importance of this tradition became very clear at a meeting with younger community members who had taken on the caregiver role: "Everyone in here knows it is our tradition to care for the person that raised us to the end of their life, and if you don't do that you are telling that person that you're very ungrateful."

In Alaska Native culture, death is part of the cycle of life. There are stories about dying people seeing and talking to deceased family members who have come to help them cross to the other side. Such stories are not generally relayed to health care providers. Aboriginal people believe

that someone who sees deceased family members is standing in both worlds getting ready to cross over. Some told stories about loved ones who were not quite ready for death: "My mother had pneumonia. Her mother and father, who had already passed, came to the foot of her bed. Her father told her it was not her time"; "A friend told me that when he was very sick, his father came to him and said in Tlingit, 'It's not your time. You have work to do yet.'"

One woman remembered that when she was 12 years old, her grandmother had died when she was alone in the house with her. Her grandmother asked her to make tea for four visitors: her husband, her son, and two others who had already passed away. She saw no one. Her grandmother then told her to "pour tea in four cups, and she was talking to them...after a while she said, 'Now it's time they're leaving.' I went over and laid her down, and she died." Another participant said, "Sometimes when I visited my mother when she was very sick, she would look in the corner and back at me and want me to leave. I know she saw her sister who passed before and wanted to talk to her."

Wisdom passed down in one community, such as that contained in the following participant comment, resonated in others: "I was told that when you know you're ready to go, you turn around the other way; you prepare yourself towards God, the way you're going to go...There is nothing in this world that will help you when you're ready to go. You prepare yourself for the road you will take when you go, because you don't have anything left in this world except for Him."

The role played by traditional healers diminished greatly as Christianity and Western medicine became more prevalent in Alaska, but it never died out completely. Today, several Alaska tribal health organizations have traditional healers, or "tribal doctors," on staff, and traditional healers sometimes help sick villagers. During a discussion of traditional practices at one focus group meeting, a participant said, "[My aunt] did a lot for the village. She was like a doctor. Every time anybody got sick they call her. At times I went with her. She'd feel the people and tell them what's bothering them, why they are sick. In those days, we only had medicine from the wild, and she told them to take them to get cured. She was important to all the people."

One commonly used term is "gifted hands." No one can explain where this comes from other than to say that from a young age, some people seem to have a healing touch. People will often speak of a grandparent or other relative who was

a traditional healer. A community health aide (CHA) said, "Training [was] passed on. [The] person with gifted hands [was] recognized, and elders looked at who they were and took them under their arm." The CHA then named the people in the village with gifted hands.

Focus group participants also provided examples of past and current practices for laying the deceased to rest. Historically, the Tlingit/Haida favoured cremation over burial methods used in other Aboriginal cultures. However, burial is now the norm: "In the Tlingit ceremonies for death tradition, the memorial service is conducted by both sides of clans. If Eagle dies, Raven clan does the ceremony. It is important that the family members are present. The more prominent the person, the more people would come. The people that are there arrange and decide who will go into the room. It is important to know who the decision maker is for the family. As the end of life nears, the main role is listening. People from the villages speak slowly, people are careful about what they say, going back to "Who's your mother, and what is your clan?" and that puts it into context. The Tlingit have many ceremonies for death and dying."

Most Alaska Native cultures have a celebratory gathering after the memorial service. The Athabaskan and Tlingit/Haida peoples will still hold a traditional ceremony called a potlatch. Each tribe has a different traditional way of holding a potlatch; some use a different name for this gathering intended to honour an occasion or thank people (25).

### Values and Preferences surrounding Death

"Culture is really important."

Alaska Native peoples mix traditional and Christian practices related to death, and the combination they use depends on which Christian organization sent the missionaries with whom they originally had contact. All of the participants expressed their belief in the circle of life and death and the expectation that family members will care for elders at home. In 2007, CHAs (predominately Aboriginal-village-based primary care providers) participated in an Alaska-wide survey on palliative care supported by the NCI grant. All 187 respondents said that elders prefer to die in their home communities.

All focus groups endorsed the view of elders as well respected and well cared for by their communities and said it was important that elders be permitted to die at home. Younger people felt it was an honour to care for their elders. However, times have changed, and villages have come to rely on the cash economy; elders are ashamed

when children and grandchildren are paid to care for them. This issue was addressed in the Helping Hands Program storybook, “Who Will Cross the River with Me?” (26) In addition to developing culturally appropriate palliative care materials, the program, by combining the best of Western medicine and traditional ways, began to help dying elders remain in their communities. People could see a dying family member or friend every day and never have to wave a last goodbye to that person as he or she left the community on a medical evacuation flight. A palliative care nurse shared her experience of helping an elder remain at home:

*Lydia wanted to go home; she knew how sick she was. I flew on a small airplane to the village once a week to visit Lydia and called her home every day. Each day, there were more stories, more symptoms, and more medication changes. On each visit, my presence was more and more accepted. With medications, Lydia’s pain, nausea, and other symptoms subsided. She was hungry — she wanted boiled fish, smoked fish. She even wanted to go ice fishing! As weeks passed, Lydia’s cancer progressed. Her family cared for her. Soon she wasn’t interested in eating and saved her energy for crocheting purses and visiting. During one visit, Lydia cried. Her pain wasn’t out of control, but she was lonely and wanted to help her daughters cope with her impending death. Lydia died at home, with her family. It was minus 30 degrees. Several village men worked through the night to dig her grave. They started a fire at the gravesite to help thaw the ground. Other men built a small casket while women in the village prepared food for the traditional village potluck. The whole village turned out for the funeral.*

These sentiments were mirrored in all the communities: “They want to be home. If you ask them, they’d rather be home”; “The elderly will live longer if they are brought back to their environment and the way they grew up”; “People want to speak their own language at the end of life”; “Hearing your language is as good as having medicine”; “Our elders, they try to pass away at home. It’s more comfortable for them...When they are close to death they want their children to be there when they’re ready to go.”

Helping when someone in the community is nearing the end of life was another recurring theme. Focus group participants were anxious to share stories about caring for people in their communities. In doing so, they expressed their own wish to die at home, cared for by family: “Whole families [would] watch over someone. Everybody had a job — brothers, sisters, uncles. Food was brought to the family”; “It is the community’s

responsibility to support people at the end of life”; “That is the tradition of our people. Usually we gather around our loved ones at the end of their life and they come from surrounding villages. I took care of my grandmother. She was 104. They were trying to put her in an old folks’ place, but I told them that it was my obligation to take care of her”; “We come together when someone needs help. It’s not a must, but it is the will of the people that you grow up with.” The desire all participants had to die in their home community was best expressed by one participant: “When my husband got sick and there was no hope, he wanted to come home...He lived three months... My sisters-in-law came to help and my daughters helped too...It’s a hard job to do, but we did it. So that’s the way I want to go.”

### Caregiver Support

“I could have used a hug, or even a smile.”

Caring for someone nearing the end of life is difficult for people of any culture. It is particularly hard in remote locations where there is little access to hospitals; limited special equipment and supplies; and a lack of trained personnel, caregivers, and respite providers. However, as evidenced by the survey results and participant comments, most people would gladly trade all of these benefits for the opportunity to die at home surrounded by family and friends. In the Alaska Native culture, family and friends are always present when a person is getting ready to “cross over to the other side.”

Caregivers in Alaska Native communities, just like those elsewhere, may not know how to ask for help, but focus group participants talked about the need for education and medical support: “I had lots of questions taking care of [my mom. It] was a learning process nobody prepared me for”; “She didn’t have the help, a nurse that could come to the house...She needed some medical support”; “Need health care providers. Help person taking care of someone. Family members don’t like to see family die”; “Provide someone to talk to regarding education about the illness and training about medications”; “Have someone come and talk to the family, right in the home. Let them know what is going to happen.” Participants also discussed those who came by to help or just visit: “Most everyone came to be with my mother, and that is a very supportive feeling you get, even when you are sad.”

Caregivers also wanted help completing paperwork, handling after-death procedures, and fulfilling advance directives. This statement reflects a sentiment expressed in several of the meetings with caregivers: “When a loved one dies, those

people [who] were so involved in taking care of them are then faced with different things that they have to deal with, like papers and getting a coffin." Developing a short information guide with step-by-step instructions for dealing with post-death tasks would be of great benefit to communities.

Advance directives are of particular concern. Do-not-resuscitate orders, and other means of fulfilling dying people's wishes when they are unable to speak for themselves, are confusing. Alaska's Native peoples are not comfortable talking about future events, and directives often go unaddressed: "I talked with my parents...They thought it was in God's hands — not up to them... Hard to get them to understand...Horrible experience with my mom. Doctors wanting to do CPR... I said no first, because that's not what Mom would have wanted. But then I've got family screaming at me — 'You're lying!'...The problem was we didn't write it down...I'm very supportive of writing it down because of what happened to me."

### **Palliative Care Program**

It is unlikely that mainstream palliative and hospice care will ever be available to most of Alaska's Aboriginal peoples due to such obstacles as the remote location of their communities, the harsh climate, and limited financial and personnel resources. However, by combining traditional community and family caregiving practices with modern medicine and telecommunications, it may be possible to establish effective palliative care programs. Education about palliative care is also crucial. It is important for people to understand that palliative care has to begin at diagnosis and continue until the end of life, and that the palliative care team includes not only the doctor and the nurse but also all those involved in supporting the dying person (27).

One of the findings from the southwestern Alaska project is that Aboriginal people do not wish to participate in trainings to prepare them to support someone nearing the end of life. Therefore, it is important to provide them with just-in-time training and support when a community member is close to death.

In 2008, a teleconference was arranged between health care providers at the Alaska Native Medical Center in Anchorage and primary clinic staff in a village 1,200 miles away who needed help in providing palliative care to a terminal cancer patient who had returned home. The clinic manager, a CHA, was excluded from the first call because the patient was her mother. It is impor-

tant to recognize the multiple roles played by village-based health care providers, most of whom are related to villagers. This CHA wanted to be a daughter first, and in her case, such a choice was possible: "How good it was to be able to be a daughter instead of responsible for the patient. My mother walked to the post office every day until 10 days before she died. It was very comforting to have the support and guidance of the health care providers in Anchorage."

In some communities, CHAs are taking steps to avoid being overburdened by end-of-life care duties, but this can be very difficult, since they are responsible for providing health care for all villagers, even their relatives. Establishing and maintaining boundaries was one of the top areas of concern in the CHA survey. After one focus group meeting, a CHA commented: We are "getting the family to help more. It was different before. There was expectation for the CHA to be there a lot. There are others now...taking on responsibility, recognizing that the CHA can't do it all. Before, we didn't have family meetings. [Now we] get together to discuss and...express the need for help...Family meetings include other family members, pastor, caregivers, and other village members. We have tried schedules for volunteer times. The CHA role is now for medical necessity, not sitting at the home." The CHA went on to say, "Pain management is a huge problem. Adequate supplies need to be sent home with patients. A patient was prescribed morphine, which was placed in their luggage and lost by the airlines. The pharmacy wouldn't send a new refill for the meds. Items like diapers and bed pads are needed, since we don't keep them in the clinic."

The information gathered in the focus groups can be utilized to create educational materials to assist caregivers and local health care providers in offering palliative care that is culturally relevant and meaningful to Alaska Native people. Recommendations for building a program of culturally appropriate palliative care include:

- Develop a short information guide that gives step-by-step instructions for handling post-death tasks.
- Recognize the importance of separating the roles of the CHA and the patient's family members; create mechanisms for regional and statewide health organizations to support individuals.
- Recognize that remote clinics do not have access to clinical and home care supplies; when patients are discharged and sent home to remote communities, provide them with adequate medications and a patient comfort kit.

- Provide just-in-time training to families and communities caring for someone who is nearing death.
- Develop ways to express advance directives that are not offensive to Aboriginal cultures.
- Conduct further research on how modern medical practices and changes in village economies have affected end-of-life care and on the benefits of combining traditional practices with modern medicine.

## DISCUSSION

Prior to setting up meeting times, village contacts would often make suggestions as to how to get more input: "You should come the day before the mail plane arrives and hold the meeting. Then go to the post office and sit and visit when everyone comes to pick up their mail." They also told the authors the best time to arrive: "Come in June before whaling season and after ice breakup. That is the time no one can get off the island." Overnight stays and visits to elders and residents before and after focus group meetings were an opportunity for one-on-one sharing and trust building. Village contacts also provided food suggestions: "The elders love smoked salmon and dried seaweed. They won't eat the seaweed in public because it gets in their teeth, so put it in separate bags to give them." Elders willingly participated in the focus groups. They provided valuable information about needs and traditional practices related to death.

The meetings varied in length, and for the most part they wound down naturally as interest waned. The shortest meeting (1.5 hours) was in the smallest community, and there was no overnight stay; this meeting yielded little information. The longest meeting (3.5 hours) began in the morning and continued through lunch. The tribal chief reluctantly ended it because another meeting was starting: "We could have talked about this subject all day." Most sessions lasted between two and three hours, with some participants lingering longer to share more information and package leftover food.

The background of the focus group facilitators was very important. The study team was "inside-outsider," because team members had already established relationships with two or more community members. The authors are also employees of the statewide tribal health organization managed and owned by Alaska Natives. "Outside-outsiders," those with no previous history in the community or organizational relationship, would likely have had more difficulty building trust during a short visit.

In contrast, this community was very receptive to the authors. Two of the authors had previously spent time there assisting with projects and building relationships. This had an impact on the community's response during the focus group meeting and informal visits.

In the small communities, participants knew one another and would encourage each other to share particular stories or tell a story from an alternate point of view, which created a rich atmosphere of sharing. Culturally, it is not Aboriginal people's way to speak directly about themselves or others on a sensitive topic. But if someone else brings up the topic, then sharing becomes acceptable. In one village, two sisters sat next to each other and talked about their mother's death and some issues surrounding it. Addressing the facilitator, one sister indirectly apologized to her sister, and her sister indirectly accepted the apology.

The authors' previously established relationships with people in the communities allowed for a more substantial flow of information at four of the six sites. It was harder to forge such connections in the larger community, where their relations were primarily with health care organization colleagues. Their reduced interaction with community members had an impact on the information gathered. Although two additional focus group meetings were held, the authors had no way of knowing whether the people who attended them were the community's revered elders. The main meeting was disjointed; discussion centred on participants' dissatisfaction with other parts of the health care system rather than on traditional practices and needs at end of life. The group was worldlier, not dependent on a traditional lifestyle, and better off financially. However, the meeting held at the Pioneer Home included elders who generally did not have the family support they needed to remain in their home villages. The information they offered was similar to that gathered from the smaller villages, often through slow, lengthy storytelling. But this meeting had a sadder note, as it was evident that participants would have preferred to be among family and friends. They missed their traditional foods and enthusiastically accepted gifts of smoked salmon and dried seaweed.

It is important to spend sufficient time in small, close-knit communities when conducting qualitative research. Rushing a visit is unacceptable. People will be gracious and welcoming during a quick visit, but they will share little information about sensitive issues. Spending the night, visiting, participating in community activities, bringing food to share, and inquiring about family

members demonstrates real interest and creates natural opportunities for information gathering.

The choice of language in which to conduct focus group meetings is important. When participants speak only a Native dialect, elders will be needed to translate for them. It is disrespectful for younger people to speak for elders in discussions on sensitive topics. One elder said that the young can only speak “baby Yup’ik.” In several communities where everyone spoke English in addition to a Native dialect, sensitive topics were still discussed in the Native dialect.

In summary, when working with Aboriginal cultures, a qualitative research approach using focus group methodology can yield significant information that would not be forthcoming if a quantitative methodology were employed. However, while still adhering to research standards, it is important to modify research methodologies to accommodate Aboriginal cultures. The authors modified the format of focus group meetings based on Strickland’s work, adopting a longer time frame and offering food and small gifts (22). The authors further suggest that a successful, culturally modified focus group methodology includes these components: informal visits before and after the meeting; and a calm, flexible approach to unexpected changes in plans. In analyzing the data, it is important to take material gathered from interviews with local residents and health care providers into consideration.

## CONCLUSION

Cancer is now the number-one cause of death among Alaska’s Aboriginal peoples. Occurrence of cancer and other chronic diseases is dramatically rising as life expectancy increases and Western culture — including lifestyle choices such as tobacco use — makes inroads in traditional communities. However, Aboriginal people have survived for thousands of years in harsh, remote regions by joining together to provide palliative care. Now, by combining traditional palliative care practices with modern medicine and technology, we can help more Aboriginal people realize their desire to remain at home when their time comes to cross to the other side.

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