

## Establishing a Culturally Sensitive Palliative Care Program in Rural Alaska Native American Communities

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### ABSTRACT

End-of-life programs that provide an option for patients to die at home are available in most U.S. communities. However, Alaska Natives living in remote Alaska villages often die alone in hospitals and nursing homes hundreds of miles away from home. The Bristol Bay Area Health Corporation (BBAHC), a tribal organization, is the sole provider of comprehensive primary care services to 34 Alaska Native villages located within a 46,000 square mile area in southwest Alaska. The closest tertiary care hospital is 329 air miles away in Anchorage. Because of the high cost of, and difficulties encountered in trying to deliver end-of-life care services to remote communities, a village-focused, culturally sensitive, volunteer and primary care program combined with a regionally based physician and home health nurse to deliver multi-disciplinary palliative care was developed. The Helping Hands Program blends cultural practices with contemporary palliative care medicine to allow Alaska Natives and others living in remote communities to be cared for at home through the end of life. Since the program was implemented in 1999, the percentage of home deaths for selected causes has changed from 33% in 1997 to 77% in 2001. The Anchorage-based Alaska Native Tribal Health Consortium (ANTHC) and the Alaska Native Medical Center (ANMC) have recognized the importance and success of the BBAHC program and are investigating expanding the program to other parts of Alaska. Centralizing the program in Anchorage will allow staff trained in palliative care to travel to regional Alaska Native hospitals to help train health care professionals.

### BACKGROUND

**E**ND-OF-LIFE PROGRAMS that provide an option for terminally ill patients to die at home or close to home are available in most communities throughout the United States. However, Alaska Natives who live in remote Alaska villages often die alone in hospitals and nursing homes hundreds of miles away from home. This practice is in direct contrast to the traditional death of their elders. Only 60 years ago, Alaska Native elders died at home, surrounded by family and friends,

in the small villages where they had lived most of their lives.

The life expectancy for Alaska Natives was 47 years in 1950, 67 years in 1984, 68.7 years in 1991, and 69.4 years in 2000, which is lower than the non-Native population for all years (Alaska Dept. of Labor). The increase in life expectancy for Alaska Natives is because of, in part, the availability of vaccines and increased access to health care services.

The Spanish Influenza epidemic of 1918 was responsible for the death of thousands of Alaska Natives. Surviving children were often placed in

orphanages in Alaska and Washington. Whole villages ceased to exist when the high number of deaths wiped out most of the population of the village. In addition, tuberculosis (TB) contributed significantly to a short life expectancy. By 1900, TB was already exacting a terrible toll in Alaska. During the first half of the twentieth century, the presence of the disease continued to increase, posing a serious threat to the survival of Alaska Natives.<sup>1</sup>

As more health care services became available, they were directed to disease prevention and acute medical services to meet the needs of the young population. As life expectancy increases, and the first generation of influenza epidemic survivors becomes elders, there is a growing need for health care services that address chronic diseases, aging issues, such as cancer and heart disease, palliative and end-of-life care. Unfortunately, a model of service delivery and funding for services, which primarily originates from the Indian Health Service (IHS), is not readily available to address health care issues of an aging population.

While the spread of Western medicine eradicated many deadly diseases among Alaska Natives, it also shifted the location of dying from the familiarity and psychosocial comfort of the home to hospitals and nursing homes. In rural Alaska, hospitals and nursing homes are usually hundreds of miles away from villages. Transport of ill patients is costly and logistically difficult. For practical reasons of weather, terrain, and distance, most villages can only be accessed by airplane travel. Terminally ill elders often spend the last part of their lives in unfamiliar surroundings and die alone without the emotional support of family and friends. Medical evacuation by airplane often signals the final departure of a village elder. Unaccustomed to detachment from nature, traditional foods, routines, and the "sterility" of hospitals and nursing homes, many elders fail to thrive and do not survive very long after they leave their village. Family and friends who live in the village are, therefore, effectively denied an opportunity to share in the elder's wisdom and knowledge and to participate in cultural practices surrounding end of life and death. For example, there are no funeral homes in Bristol Bay villages, and when someone dies a natural death in the village, burials are handled by village residents. It is difficult for them to bring closure to a loved one's death. Grief is often compounded and complicated.

Because of the high cost of and difficulties encountered in trying to deliver end-of-life care services to remote communities, a village-focused volunteer and primary care program was developed that combined with a regionally based physician and home health nurse to deliver multidisciplinary palliative care. The Helping Hands Program blends cultural practices with contemporary medicine to allow Alaska Natives and others living in remote communities to be cared for at home through the end of life.

## POPULATION/SETTING

The Bristol Bay Area Health Corporation (BBAHC), a tribal organization, is the sole provider of comprehensive primary care services to 34 Alaska Native villages, located within a 46,000 square mile area in the Bristol Bay area of southwest Alaska. The Corporation manages and operates Kakanak Hospital (15 beds) for the IHS. The hospital and BBAHC's administrative offices are located in Dillingham, 329 air miles southwest of Anchorage, and the location of the closest tertiary care hospital. Bristol Bay area villages are only accessible by small airplane or, seasonally, by boat. Harsh weather conditions and difficult terrain further limit the ability to provide medical services. Close to 100% of Bristol Bay area residents (Native and non-Native) receive some form of health care from BBAHC either in the villages or at Kakanak Hospital. Even when they are referred to the Alaska Native Medical Center (ANMC) in Anchorage (the tertiary care center for all Alaska Natives), visits are also entered into the BBAHC database. Subsequently, BBAHC's database represents an accurate depiction of disease incidence and outcome for Bristol Bay area Natives and many of the non-Natives who make up 29% of the area's population.

The villages, which range in size from a population of 22 to 2466, are 71% Alaska Native, primarily Yup'ik Eskimo, Aleut, and Athabaskan Indian (U.S. 2000 Census). The majority of villagers participate in a subsistence lifestyle, dependent on hunting, fishing, and gathering for a large part of their food supply.

Health care is delivered through an integrated system of care by local and regionally based health care providers. Village residents, trained as community health aides/practitioners (CHA/P) deliver primary care services at small village clin-

ics. The clinics operate under BBAHC standard protocols. Pharmacy protocols include a locked box to store opioids and other controlled substances. Health aides work under the guidance of a physician assigned to each village. The assigned physician and health aide develop a strong working relationship and the physician is able to determine the health aide's level of medical skills and comfort with medical problems presented. The directing physicians are located at Kananak Hospital (eight physicians) in Dillingham or ANMC in Anchorage. The assigned physician visits the village four or five times per year to see patients who come to the clinic and provides home visits when needed. In most villages, the health aide is related to many of the villagers, which can make confidentiality and dealing with trauma and death even more difficult. The physician makes daily contact with the health aides via telephone, radio, fax, or computer.

In 2 of the 34 Bristol Bay communities, the clinic staff also includes a nurse practitioner or physician's assistant. Dentists, audiologists, and optometrists travel to the villages to see patients once or twice each year. Other village-based workers include community health representatives (CHR) who provide health education, and family service workers (FSW) who provide paraprofessional mental health and support services. For surgery and other complex care needs, residents must travel by airplane to Dillingham or Anchorage. There are no nursing homes in the Bristol Bay area and only a single assisted living facility in Dillingham.

Itinerant public health nurses also travel to the villages to provide immunizations and other services. A tribally operated social service agency, Bristol Bay Native Association (BBNA), provides durable medical equipment (DME) and trains personal care attendants (PCA) to help elders with chores, bathing, and other needs. Depending on the patient's home village, DME is also provided through Anchorage and the Native corporation in Bethel. Quarterly interagency meetings serve as a mechanism for all agencies and providers to work together to identify gaps in services and develop a way to meet specific patient needs.

### PROGRAM DESIGN

The Helping Hands Program is based on Alaska's successful emergency medical service

(EMS) model. It includes trained volunteers and caregivers in the villages with medical direction and technical assistance provided from a central location (Dillingham or Anchorage). Village-based health care providers receive palliative care training. They have generally lived in the village most of their lives and are often related to many of the villagers.

A survey of Bristol Bay area CHA/Ps conducted in 1994 indicated an overwhelming desire (84 %) for end-of-life care training. Sixty-six percent of respondents believed that families who were taught to care for dying patients at home would experience reduced alcohol abuse around deaths.

An advisory group, which included agency representatives, public health nurses, Alaska Native villagers, physicians, and others, was formed to help design the program. The feasibility of the Helping Hands Program eventually becoming a Medicare-certified hospice program was explored.

The development of culturally sensitive program materials was an important part of program design.<sup>2</sup> BBAHC had previously experienced a lack of success when trying to use mainstream program materials in a tobacco cessation program. A literature review revealed little material that addressed end-of-life issues in American Indian/Alaska Native populations. A literature search failed to identify similar programs in other parts of the United States.

Focus groups with elders from the three Native cultures were scheduled to aid in actual program design and materials development. Additional focus groups comprised of villagers sent away to boarding schools who were unable to return home (because of lack of funding or school rules) to visit their terminally ill family members, were also planned. Focus group techniques were tested and refined before meetings were scheduled.<sup>3</sup> Village tribal councils and village senior services were notified about the meeting and their support requested. Village elders do not respond well to strangers coming to the village and requesting sensitive information. Therefore, a medical anthropologist who had worked with village senior service programs and the BBAHC director of planning and communications facilitated the focus groups. Focus group findings provided key information that was incorporated into program materials and design.

The program design depended on a protocol for identifying a primary caregiver for each patient, training village-based workers, and the de-

velopment of a cadre of trained workers and volunteers in each village. CHA/Ps, FSWs, and CHRs received training on end-of-life issues. A home health nurse would visit each patient on a regular basis and provide telephone support between visits. Patient care plans that incorporate basic village resources would have to be devised. Program participants do not have access to support services such as physical, occupational, and respiratory therapy. Getting DME to the village can be difficult. For example, loading a large, cumbersome hospital bed on a small airplane and flying it to the village, unloading it and transporting it to a patient's home is time consuming and difficult.

The focus of the program was pain and symptom control combined with training for family, health care providers, and volunteers. This project was designed to deliver needed medical services to improve community and prospective care planning consistent with the needs, values, and preferences of ill persons in a culturally sensitive manner.

The program was designed to combine contemporary palliative care with the traditional ways of an indigenous culture to provide an option for elders and others nearing the end of life. While the program was not designed to make a profit, it was developed with the belief that providing at-home care during the traditionally medically expensive last part of life, and avoiding expensive medical evacuations by airplane and hospital stays, could reduce overall health care costs while improving quality of life and family experience.

Selected program materials were translated into Yup'ik and recorded on an audiocassette to help non-English speaking village elders understand the program. Yup'ik is the primary language of many of the Bristol Bay area Natives. Many Aleuts and Athabaskan Indians speak at least a small amount of English. This is variable by region and in some areas of Alaska, few residents speak English.

## PROGRAM EVOLUTION

The Helping Hands Program was recognized as important and welcomed by the people of Bristol Bay, as well as local health and social service providers. There is no programmatic competition for a palliative care program in an area where

health care services are expensive and difficult to deliver.

As program delivery design progressed, it became evident that the Helping Hands Program would never be able to meet existing state and federal rules and regulations regarding hospices. A particular limitation was the need for nurses to be able to reach a patient within one hour, literally impossible in most of the region. The initial concept of adhering to formal hospice regulations and seeking Medicare certification was therefore abandoned.

Elders willingly participated in the focus groups. They provided valuable information and perspectives regarding needs and traditional practices around death. It was important for focus group facilitators to remain in the village overnight to provide an opportunity for additional one-on-one discussion. Some of the most valuable information, which proved critical for successful program design, was not revealed during the focus group but later in the day or evening. For instance, we learned that it was difficult for elders to understand why their grandchildren, who had received PCA training, were "paid" to take care of them. They were ashamed when "outsiders" took care of them instead of family. This information was incorporated into a story used in program materials.

The first focus group of caregivers who had been away at boarding school when a family member died proved to be difficult. Boarding school memories are still too painful for many American Indians/Alaska Natives. Questions about death and dying brought forth unpleasant memories. It was difficult for facilitators and participants to watch men and women openly weep as they still struggled decades later to find answers to the unanswerable questions they had regarding why they were not allowed to come home when a close family member died. Although this focus group was meaningful to participants and uncovered significant unresolved grief, it did not contribute significant useful information for program design. It was not repeated in other communities.

Implementation of the program took much longer than anticipated. Staff turnover in the key nurse coordinator position added delays. The reality of living in remote communities with primitive Third World conditions, the need for constant and perilous travel on small planes, and the challenges of coordinating medical care with lim-

ited resources was problematic to individuals who accepted the position. A number of focus groups were cancelled and rescheduled due to weather. A plane crash in one village the day before a focus group was scheduled killed five people, including two key elders who planned to participate in the focus group. It is considered disrespectful to visit a village during mourning times and the focus group was rescheduled several months later.

Once the program became operational, an early observation represented a positive outcome and a programmatic challenge. Far more patients than anticipated became Helping Hands patients as the word spread about the program. Elders who had moved to Anchorage to get health care services for chronic and other medical problems moved back to their villages. Physicians at ANMC and Kakanak Hospital allowed patients to go home because the Helping Hands Program could provide care for them at the end of life. Back in their home surroundings, patients thrived and survived much longer than expected.

Other unexpected problems surfaced. The subsistence lifestyle that requires villagers to leave their homes in summer and travel to rustic fish camps created problems of caring for infirm and frail elders left behind. Villagers were not interested in attending training in end-of-life care unless someone in the village was nearing death. Subsequently, plans for region-wide training were abandoned. Planned evaluation measures were too cumbersome and villagers were not willing to participate in post-death telephone calls.

Occasionally, patients returned to the village without the Helping Hands Program staff knowing about their return. In one instance early in program implementation, health aides and family panicked and a dying elder was evacuated by airplane, only to die during the flight to the hospital, compounding the grief of the family.

### STRATEGIC RESPONSES

As program design and implementation moved forward, the initial concept proved to be sound. Decentralized services with central technical support and home health nurse visits were effective program components. Patient care plans were devised to incorporate traditional lifestyles.

With the assistance of the program's evaluation mentor, provided by the Robert Wood Johnson

Foundation, evaluation measures were simplified. For instance, rather than trying to conduct post-death telephone interviews, the study protocol was modified to have the nurse or volunteer coordinator involved in the case conduct interviews with survivors during a visit to the village.

A nurse program director/principal investigator was hired to complete program development and worked with other staff to move the program forward. An Alaska Native volunteer coordinator was hired and based in Clarks Point, a village close to Dillingham. Program materials were designed and used to educate and train patients, families, staff and volunteers.

Many of the region's 80-plus CHA/Ps who attend annual training on a rotating basis in Dillingham were introduced to palliative care and caring for elders in the village who were nearing the end of life. When the home health nurse and volunteer coordinator traveled to villages to see patients, they also spent time with CHA/Ps answering questions and providing informal one-on-one training.

The principal investigator and volunteer coordinator traveled to Anchorage and met with ANMC medical, nursing, and social service staff to explain the Helping Hands Program. Because most of Alaska's Native patients can only receive tertiary diagnostic and treatment services at ANMC, it was important for ANMC leadership and clinical personnel to know that Helping Hands palliative care services were available in Bristol Bay villages.

Family caregivers were eager for information that helped them understand what was happening to their loved one. The home health nurse was able to respond to concerns by telephone and during village visits. A comprehensive study on the need for medical evacuation for patients in the program was not completed. However, anecdotal information based on telephone conversations between patient caregivers and palliative care nurses indicated, that for at least some of the patients, the nurse, with physician concurrence, was able to reassure the caregiver and provide instructions that allowed the patient to remain in the village. Elders were pleased that they now had an option to remain at home in familiar surroundings as they neared the end of life.

Since receiving education on pain control, the medical staff has been more supportive of the program. They are also better able to provide medical direction for end-of-life care.

Rather than remain a separate program, the Helping Hands Program was redesigned to remain part of the home health program to better address the longer than expected life of patients who returned to their home village. Care plans were developed around patient goals and the realities of an existing lifestyle. For instance, berry picking was encouraged to promote healthy eating and exercise for patients with diabetes.

Working with BBNA, PCAs now visit more often when families are away fishing and hunting. Program staff will work to make sure volunteers are available to provide meals and other needs during subsistence times.

### DELIVERING CARE THROUGH THE HELPING HANDS PROGRAM

There are many ways for a patient to be referred to the Helping Hands Program. The most common way is through physician referral. However, other BBAHC staff, families, friends, or other agencies can refer patients.

Once a patient is referred to the program, the home health nurse reviews the patient's medical record, receives a doctor's order for a home visit, and then contacts the patient and family to schedule an initial visit. The nurse also notifies the village health aide. (S)he travels on a small plane to the village with the volunteer coordinator and visits the patient at home. If the patient is being discharged from the hospital, the nurse may travel home with the patient. When a patient is admitted into the program, the following steps take place:

- Assess patient needs: DME, pain management, physical assessment, caregiver availability/stability, need for and willingness to accept PCA services and volunteer assistance.
- Determine patient goals, which may be different for health care provider and patient.
- Develop individual care plan that supports the village lifestyle.
- Establish trust.

The nurse meets with the patient's physician who orders medications, including analgesics when indicated, and other services. The nurse coordinates DME needs with agencies located in Dillingham, Bethel, or Anchorage, depending on the location of the patient's home village. The volunteer coordinator meets with the patient and

family and determines the kind of support needed. She also works with the village council and others to identify and schedule volunteers.

Volunteers, caregivers, and CHA/Ps receive printed materials designed for their specific role in end-of-life care. The guides are designed to serve as a reference tool, and help answer family and village-based health care provider questions when the nurse is not in the village.

The nurse tries to visit once a week, depending on client load, weather, and patient need. At other times, communication is by phone or radio. The nurse also makes regular phone calls to check on the patient. Caregivers, health aides, and volunteers call the home health office with questions and concerns. During evenings and weekends, caregivers can call Kakanak Hospital and talk to a nurse or physician. Physicians make home visits to the patient during regularly scheduled village visits which occur four or five times a year.

As a patient's condition worsens, the nurse may spend additional time in the village with the patient and family. When trust is established, it is easier to talk about do-not-resuscitate (DNR) orders, Living Wills, and other tools. If the nurse cannot be there for the patient's death, she usually arrives shortly afterward and attends the patient's funeral, if requested by the family. After death, follow-up visits occur for grief support as well as to conduct an after-death interview. Because there are no funeral homes in Bristol Bay, the nurse is frequently called on to help prepare the body for viewing and burial.

An important component of the volunteer program is the involvement of village youths. Approximately 10 villages (the number varies each year) have teen peer groups, called Peer Helpers. The prevention-based program, funded by the state of Alaska, is designed to help teens avoid substance abuse and suicide. As part of their orientation, Peer Helpers receive training from the Helping Hands program volunteer coordinator in order to provide support to terminally ill elders. In addition to helping with chores and respite care, an important function of the teen volunteers is the recording of traditional knowledge and experience into the journal each patient receives. This is especially important, since many elders do not write, but are willing to share life experiences orally. In villages without Peer Helper programs, individual village youths are recruited as volunteers. The program makes a significant cultural contribution in that it helps restore old traditions

of caring for people in the community, honoring elders, and supporting each other through the grieving process.

Number of deaths and service utilization data pre and post Helping Hands Program implementation were gathered. Between 1997 and 2001, the number of deaths from all causes ranged from 33–47 (Table 1). Seventy-seven percent of the patients diagnosed with cancer, chronic obstructive pulmonary disease, congestive heart failure, or renal failure who died in 2000 or 2001, died at home as opposed to 33% prior to program implementation (Fig. 1). Sixty-two percent of decedents with these same diagnoses were Helping Hands patients. Seventy-seven percent died at home. The number of patients with DNR orders, or Comfort One out-of-hospital orders in selected diagnoses also dramatically increased when the program was implemented (Fig. 2).

Acceptance and understanding of the program can be difficult to measure in a quantitative fashion. Postdeath interviews indicate that caregivers were glad their family member was able to remain in the village. Anecdotal evidence suggests that both understanding and acceptance are growing. In one village, a widow whose husband was one of the first program deaths went to visit and help a woman whose husband was near death. In another village, when the home health nurse went to complete an assessment on a terminally ill cancer patient, he said, “I can stay home like John did, right?”

As grant support for program development

TABLE 1. DEATHS IN BRISTOL BAY, ALASKA, BY CAUSE

	1997	1998	1999	2000	2001
Trauma	6	9	18	9	21
Aneurysm	2				1
Cancer	7	4	6	6	9
Cardiac arrest	4	6		1	6
Renal failure	2	1	1	2	3
Stroke	1		2	2	
COPD/CHF		3	7	5	1
Stillborn/birth defect		1		1	2
Septic shock		1		1	
HIV			1		
Postsurgical	2				
Unknown	9	9	4	9	4
Total	33	34	39	36	47

Source: BBAHC Health Information Database  
 COPD, chronic obstructive pulmonary disease; CHF, congestive heart failure; HIV, human immunodeficiency disease.

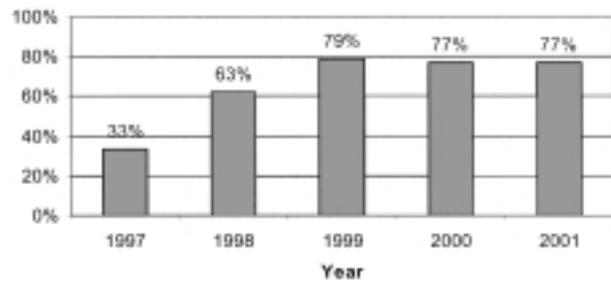


FIG. 1. Bristol Bay Area Health Corporation (BBAHC) Patients deaths for selected causes: cancer, chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), and renal deaths. Percentage of Deaths at Home. Source: BBAHC Health Information database.

concludes, it is important that villagers take initiative to continue the program. It is equally important for the BBAHC Board of Directors, which is made up of one elected representative from each village, to recognize the importance of providing financial support to continue the program.

### GENERALIZABILITY

The concept and design of the Helping Hands Program is transferable to other indigenous populations and remote communities in Alaska and beyond. The program utilizes the existing rural health care delivery model to expand the continuum of care rather than introducing a new model. Incorporating end-of-life care into the existing model increased its scope and enhances its generalizability.

Several key lessons are likely to contribute to success for similar programs:

- Adapting standard tools, such as evaluation methods and focus groups, to fit a specific population’s lifestyle and traditions.
- Identifying concerns about changing traditions and how they will affect program success.
- Adapting standard care plans to better reflect patient goals and lifestyle choices and incorporating customary and traditional lifestyle activities into care plans.
- Assuring community buy-in by soliciting information before program design is complete.
- Providing opportunities for agencies and individuals to participate in the program and helping to guide the process to determine what is or isn’t working.

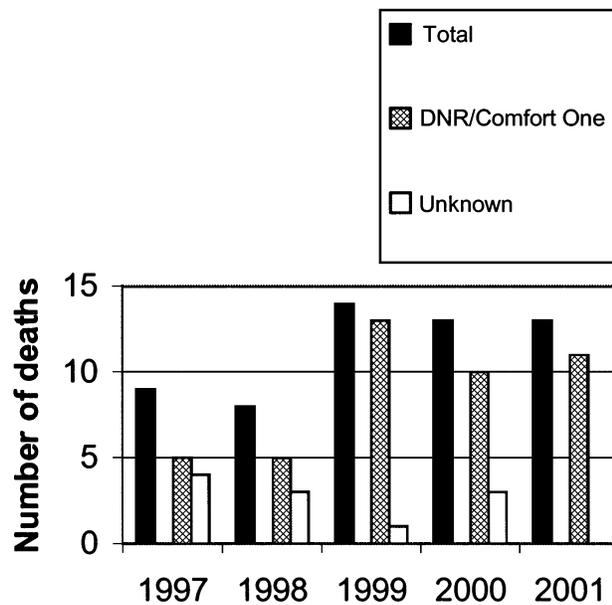


FIG. 2. Deceased patients with do-not-resuscitate (DNR)/Comfort One signed documents. Source: Bristol Bay Area Health Corporation (BBAHC) Health Information database.

- Integrating all health care and social service resources is critical to providing culturally sensitive, quality end-of-life care.
- Striving for institutionalization of the program as soon as possible. If the program start-up is grant-funded, early incorporation within the standard protocols, procedures, and practices of the host institution helps ensure program sustainability.
- Being flexible, innovative, and patient.

The most important finding of Helping Hands Program implementation is that contemporary palliative care combined with traditional customs can create a cost-effective, culturally sensitive, palliative care program. By developing a program that incorporates a traditional way of life, indigenous people and others living in remote settings can remain at home, in familiar surroundings, as the end of life nears.

### SUMMARY

State and national government policy makers, licensing agencies, and other organizations that impact the delivery of end-of-life services need to better understand that the ability of health care organizations to meet the needs of the people is

not always based on the delivery of the latest medical techniques and services. Such services can be difficult to deliver as well as prohibitive in cost. As this experience with Alaska Natives indicates, certain populations in the United States do not receive the same level of care because of geographic or ethnic disparities. Medicare and Medicaid regulations governing hospice care do not allow for flexibility to accommodate the needs of underserved populations and locations.

The realities of staff turnover in this isolated region require that the program be institutionalized within BBAHC to be sustained. Palliative care training must become a standard component of village-based and hospital provider training. BBAHC's home health program is critical for continuation of the Helping Hands Program. The village coordinator position must continue in order to maintain a corps of individuals trained and available to assist when someone enters the program. Ongoing education must be made available to CHA/Ps.

The Anchorage-based Alaska Native Health Consortium (ANTHC) and the ANMC have recognized the importance and success of the BBAHC program and are investigating the possibility of expanding the program to other parts of Alaska. Centralizing the program in Anchorage will allow staff trained in palliative care to travel to regional Alaska Native hospitals on a regular basis. They will be able to provide continuing education in palliative care and help train new staff, the need for which occurs frequently, due to the high turnover rate in health care professional positions in remote Alaska communities.

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**APPENDIX A. HELPING HANDS PROGRAM DEVELOPS  
CULTURALLY APPROPRIATE MATERIALS**

Mainstream America palliative care materials, particularly those designed for the lay public, did not meet the needs of Alaska Native elders. These elders cannot relate to the depiction of mainstream American life, people, and activities of daily living. BBAHC has had previous unsuccessful experiences in trying to use material developed for a mainstream American audience (e.g., smoking cessation). As a result, a number of items were developed to aid in the understanding and acceptance of the Helping Hands Program.

- **Program brochure**—Describes the program and how it integrates traditional ways and contemporary medicine.
- **Volunteer brochure**—Explains how volunteers can provide valuable help as someone nears the end of life. It describes customary and traditional ways of helping, such as bringing in firewood, smoking fish, and picking berries.
- **Program flowchart**—Alaska Natives are highly visual people and are not generally linear thinkers. The flowchart developed uses pictures to show the interaction of everyone who helps someone remain home at the end of life. The reverse side of the graphic uses icons from the flowchart to describe the functions and activities depicted. This visual approach allows the program to be incorporated into other areas that use different names to describe functions.
- **Who Will Cross the River with Me?** storybook—As Native elders near the end of life, they often refer to “crossing a river.” The book incorporates findings from the focus groups to describe a situation in which an elder is able to remain at home at the end of life. It incorporates a number of nuances of life in the village that are important to remember when an outsider comes into the village (e.g., always remove shoes at the door, sit down to have tea and talk, examine a patient in the presence of family and friends). The book is narrated in English and Yup’ik by a Yup’ik storyteller and linguist and available on an audiocassette (many Native elders cannot read). Note: while there are three main Alaska Native groups in the Bristol Bay area, the predominate Native group is Yup’ik Eskimo, which also has the largest number of non-English speaking elders.
- **Journal**— “When you are caring for someone who is dying, you don’t have time to record his/her memories or stories or those of friends,” said a local nurse who is also a recent widow. The journal includes relevant prayers and poems, primarily Native American, sections for “Friends’ Thoughts” with memory reminders such as “One of my favorite conversations with you . . .” and “When I eat\_\_ I think of you . . . .” and a section for the patient with headings such as “What I want people to remember me most for is . . . .” and “What I will miss most is . . . .” The journals also include a place for a family tree. Because many of the elders were orphans (their parents died during the Spanish Influenza epidemic), their families have a chance to gather history for younger generations. In one instance, a nurse took her husband along to visit a patient. The patient had grown up in the orphanage with the nurse’s husband’s father and was able to recount stories of his life as a young person.

Early results have shown that the journals are being used in a number of ways. Family and friends have filled some journals with memories. Others include elder stories recorded by visitors and teen volunteers. Some remain open in the assisted living facility for people to write in as they wish. One of the early recipients was dubious of the value of the journal and skeptically paged through it. Suddenly he started telling a story of his youth and began smiling and laughing. It was the first time he had laughed in a long time.

The journals are very popular outside the program and have a much broader scope of relevancy than anticipated. Proceeds from the sale of the journal will help in a small way to offset the costs of continuing the Helping Hands Program.

- **Pain scale**—The scale, a modification of the Wong Baker Faces Scale, uses Alaska Native faces for the six-face scale. It has English and Yup’ik translations below each picture. The scale is easy to

use and can be used by the patient and family during a nurse's visit or when the nurse calls on the telephone to discuss the patient's status.

- **Caregiver, volunteer, CHA/P guides**—Looseleaf notebooks provide information on how to care for patients nearing the end of life. While they contain many of the same materials that mainstream guides include, traditional knowledge and wisdom sections are also included as well as practical information that addresses caring for patients in a remote setting. The CHA/P guide duplicates portions of the guide CHA/Ps use to provide care as well as additional information. The caregiver guide includes a special first page "How to take care of\_\_\_." The patient's name is written on the page as well as contact telephone numbers for nurses and the volunteer coordinator. A section on Native plants and medicines is also included in the guides.