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Annual Elders Issue

This May issue of The IHS Provider, published on the occasion of National Older Americans Month, is the seventh annual issue dedicated to our elders. We are grateful for the opportunity to honor our elders with a collection of articles devoted to their health and health care. Indian Health Service, tribal, and urban program professionals are encouraged to submit articles for the May 2003 issue on elders. We are also interested in articles written by Indian elders themselves giving their perspective on health care issues. Inquiries can be addressed to the attention of the editor at the address on the back page of this issue.

Rural Affordable Assisted Living in Dillingham, Alaska

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Background

With a population of 2,500, Dillingham is the largest community in the Bristol Bay region of Alaska. Bristol Bay is located in rural Southwest Alaska, approximately 400 air miles from Anchorage (inaccessible by land). The region has a limited road system connecting only a handful of villages, and covers a landmass of 40,000 miles. According to the 2000 census, the population of the region is 7,700, which is disbursed throughout 32 villages. There are approximately 500 people over the age of 60 in the region, most of whom are low income and receive some type of public assistance.

Grandmothers House

Marrulut Eniit (Yup'ik for Grandmother's House) is a ten-unit assisted living facility that opened in Dillingham, Alaska in February 2000. The emotional open house ceremony demonstrated the strong desire that this community has to keep

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their elders as close to home as possible throughout their lives. In rural Alaska, this is not always possible. Most often elders are relocated to nursing or assisted living homes in Anchorage or other Alaskan communities. This means that an elder is removed from their culture, their way of life, and their family. This causes a great deal of stress for both the elder and family members who cannot travel to visit their loved one as often as they might like.

Marrulut Eniit Assisted Living (MEAL) is a step toward changing this occurence in one rural community. Although the development process was long and arduous, it has been well worth the effort of the people and organizations involved.

The process began in fall 1996 when the Bristol Bay Native Association (BBNA) received predevelopment funding from the State of Alaska, Division of Senior Services, to conduct an assessment of the need for assisted living in the Bristol Bay region and to develop a plan to meet that need. BBNA organized a steering committee, comprised of individuals from the agencies providing services in the region, that took on the oversight of the needs assessment contract.

The needs assessment project included holding community forums in five regional villages to provide information about different types of housing and services, and to elicit opinions from residents about the development of services. Community members were interested in services that would assist individuals to live in their own home and village as long as possible, provided by local people familiar with the language and culture. One of the dominant themes that emerged from the community forums was that everyone wanted an assisted living home in their own community. However, by general consensus, people did think that having a home built in Dillingham would be better than moving outside the region. Thus, the steering committee decided to pursue developing a conservative ten-unit home in Dillingham, and later to investigate the possibility of smaller two- to five-unit homes in other villages.

Funding

Curyung Tribal Council in Dillingham became the first agency to offer funding to begin the development phase of the project. They awarded BBNA $25,000 of their Bureau of Indian Affairs compact funding to pursue the development of an assisted living facility. Working with a developer, the next step was to apply for capital funding. The Bristol Bay Housing Authority applied for funding from the Alaska Housing Finance Corporation, and received a Senior Citizens Housing Development Grant for $900,645. Additional funding was obtained from the Alaska Mental Health Trust Authority, the Federal Home Loan Bank, and two $500,000 HUD Indian Community Development Block Grants (ICDBG) awarded to the tribes of Dillingham and Ekuk. The total funding for predevelopment, construction, and furnishings was $2,323,645. The City of Dillingham donated a prime piece of property in the immediate vicinity of downtown, and across the street from the local senior center and independent apartments. Construction began in summer 1999, and Marrulut Eniit became home to its first resident in February 2000.

To decide on the features of the building, the steering committee revisited the community forums to determine what the elders wanted. The final design includes ten private apartment units, each with a small kitchen and dining area, a living room and bedroom separated by a pony wall, and a bathroom. Four of the units are handicapped equipped; the remaining six are accessible. The rooms foster privacy and independence, but many residents choose to leave their doors open and readily welcome visitors throughout the day. All rooms are furnished, and residents are encouraged to bring things from their home.

Common spaces include a commercial kitchen, a dining area with activity space, another small congregate sitting area for the residents, and a covered outdoor seating area. The common areas are bright and cheerful; the dining room offers full-length windows so residents can gaze toward the river. The kitchen facilities are adequate for the size of the home; storage for additional freezers and supplies is located in an adjacent building. A specialized whirlpool tub that has become a favorite among residents was purchased with remaining development funding.

Since the funding package for construction is made up entirely of grants, there is no debt service owed by MEAL. However, there are still challenges to providing quality assisted living services in rural Alaska. For operational funding, MEAL looks to several sources, including the residents' income and Project CHOICE, Alaska's Medicaid Waiver program. Residents' income will pay for room and board, with the rent charge set according to their income, and food costs set at approximately $365 per month. The service component comes from Medicaid, depending on the need of the resident and averaging $2600 per month.

Ownership

This project continued to be a joint effort between the agencies represented in the steering committee. Without the commitment of these agencies, the project would not have been possible. Each of the agencies signed Memoranda of Agreement. These MOAs not only identified their commitment to the project by identifying their services for the facility, but also specified financial support if the facility needed it in the future. All regional providers understood that for an assisted living home to be financially feasible, the costs needed to be limited.

Since most of the provider organizations in the region are nonprofit agencies with strict guidelines on their funding streams, it was difficult for any one organization to take on the development of assisted living. In answer to this dilemma, a separate 501(c)3 nonprofit organization was established that would own and operate the home and oversee the construction aspects. The Board of Directors for the newly formed nonprofit organization included representation from all the

regional provider agencies that contributed funds or services to the facility, each bringing with them the expertise of their agency.

The Bristol Bay Housing Authority offers experience in housing construction and management and provides a management contract that includes the ability to provide MEAL staff with fringe benefits. The Bristol Bay Native Association provides care coordination to residents and offers personal care attendant training for staff. The Bristol Bay Area Health Corporation is the primary health care provider and offers home health services. The City of Dillingham donated the land for the building and operates the local senior center, which provides lunches five days a week to residents at MEAL. Curyung Tribal Council and Ekuk Natives, Ltd. have representation on the board because of their ties to the local elders and their ICDBG funding. The last member of the board is an elder selected from the community. In addition to the agency expertise made available through the composition of the board, choosing members from each agency also helps to alleviate boundary issues between organizations as they work together on a common project.

Operations

MEAL offers a full spectrum of assisted living services in a clean, pleasant environment that is culturally sensitive to area residents, most of whom are Alaska Native. They currently house ten residents ranging in age from 61 to 101, with the majority between the ages of 85 and 95. MEAL is currently receiving maximum Medicaid reimbursement for all residents, indicating that they are caring for individuals with very complex care needs who would otherwise be eligible for admission into a skilled nursing facility. Four of the residents require total care, including assistance from two staff to transfer from bed to bathroom or wheel chair. Half the residents have some form of cognitive decline, with two being very advanced in their dementia and requiring additional supervision.

The home administrator lives in an apartment on site and is responsible for the day-to-day operations. MEAL is staffed 24 hours a day, utilizing the universal worker concept. Universal workers are cross-trained in a variety of duties so they can step into any position needed. All staff are required to provide hands-on care to residents. Most of the staff are from the Bristol Bay area and some speak their Native language. Nurses and Physical Therapists from the Bristol Bay Area Health Corporation, State of Alaska Public Health Nursing, and the Bristol Bay Native Association provide specific training to staff for residents with more intensive care needs.

MEAL is designed, both in physical structure and philosophical commitment, to allow elders to age in place, as evidenced by the high level of care required by of many of the residents. To date MEAL has not transferred anyone to another facility for care.

"Grandma's House has filled a much needed void in the Bristol Bay region. Marilyn as the director has done an incredible job of keeping the residents at 'home' in all circumstances. She feels that they are at home at Grandma's House and that they deserve to remain at 'home' until the end of their lives." Kristina Jones, RN, MPH, BBAHC Home Health

This philosophy has created a challenge for the MEAL Board and staff. They realize now that it is important to achieve a balance between residents with high-level needs and those who can do more tasks independently. The home now limits the number of non-ambulatory, two-person transfer residents to three, in order to be sensitive to the needs of other residents and reduce the impact on staff.

Community Support

From the beginning, there has been tremendous community support for this project. Keeping elders close to home is an issue that people could readily rally behind. Community support is evidenced in the collaborative work of the agencies involved in the development process. That support has continued and grown since MEAL opened.

"Grandma's House is a constant reminder of how successful we can be as a community and a region, that if we work together we can overcome any obstacles." Chris Napoli, Mayor, City of Dillingham

Bristol Bay is home to a culturally diverse group of Alaska Native people who traditionally hunted, fished, and gathered berries as a way of life. This continues today as families practice their traditional subsistence lifestyle that includes a rich blend of cultural foods available seasonally throughout the year that are prepared in various ways for storing. Elders of the area prefer a diet based on these traditional foods. MEAL staff has been overwhelmed with donations of traditional food from area residents. Although one freezer for traditional foods was planned for the project, they had to purchase an additional one almost immediately to accommodate the volume of donated meat and fish. They receive donations of salmon, moose, caribou, and seasonal specialties such as herring eggs and seal oil. This outpouring of generosity helps maintain MEAL's food budget in an area where grocery store prices are extremely high.

Residents from the local community take great pride in the facility and the elders residing there. The first summer a local family came by and asked if they could clean up the yard – they wanted a project they could do together and to help the elders in the process. Since then families with residents in the facility, and others wanting to honor a loved one, have planted a perennial garden, including a variety of flowers and berry bushes that flourish during the Alaskan summer. Birdhouses and bird feeders that provide residents with

some entertainment were donated and placed around the building.

Local churches are also involved. The Russian Orthodox Priest provides regular communion for residents, and there are visits by other pastors as well. Local groups come to visit with elders and entertain with music and dancing. The Head Start children and junior high Native dance clubs provide opportunities for residents to watch and participate in traditional Native dancing.

Replicability

MEAL is a solid model of what a community can do if they work together on a project. The State of Alaska is working to replicate the model in other regional hub communities. Aspects that would make it more easily replicable in other parts of the country are lower construction costs, longer construction seasons, and lower operational costs. The model is compatible with needs in other rural areas of the U.S., such as where residents are disbursed over a large geographic area, where health care and social services are provided from a central location, and where there is a need for collaboration to achieve economies of scale. As more states provide funding for services for assisted living through Medicaid waivers, more low-income rural residents can be served.

Challenges and Lessons Learned

Following are some of the important lessons learned in the development of a rural assisted living home and its ongoing operations. This section will also be useful for communities desiring to replicate the facility.

- Recognize the importance of working with medical staff to develop an understanding of assisted living as a social model of care. During the community forums, hospital physicians were against the development of an assisted living facility in Bristol Bay that was going to provide total care without employing medical staff. They favored instead a skilled nursing facility. Even with education about assisted living, there was still lingering doubt among some of the medical staff when the facility opened. The competency of the administrator and staff were put to a test with the admission of the first resident. As the staff proved their ability to provide adequate care, medical staff became some of the most vocal supporters of MEAL.

  The first resident admitted was a swing bed patient with a recently fractured hip. Medical staff discouraged placement in MEAL because of the patient's high needs. In only a few months, the resident's condition had improved dramatically and she was able to get from the bed into a wheelchair to attend her granddaughter's wedding.

- To make a project like this financially feasible it is important to use a variety of funding sources. However, it is important to recognize the restrictions that apply to each source. One challenge for MEAL was the restriction that only people 60 years of age or older could reside in the facility due to the funding from the Alaska Housing Finance Corporation. Since the project is the only one of its kind in the region, MEAL wanted the flexibility to offer services to all people needing assisted living. Since there were other funding sources we felt that a portion of the facility could be used for younger, disabled persons. A solicitor's opinion indicated that we were wrong, and that the strictest guidelines apply to the entire facility. Therefore, we learned the importance of identifying funding sources that are more flexible and have fewer restrictions.

- The collaboration between agencies and the development of a separate nonprofit organization to own and operate the home are two of the keys to its success. This fosters active involvement from all service provider agencies and mitigates any conflict about who is responsible. One challenge of forming a new nonprofit organization is the lack of financial and management experience. Having support from the various agencies is a very important component of this structure to be able to gain experience while utilizing the existing experience of board members.

- The development of a dependable workforce is crucial to the success of a rural assisted living home. Staff turnover remains the biggest challenge for MEAL (as it is with the long-term care industry throughout the country). It is essential that the planning committee identify employment resources at the beginning of the project and ensure that adequate training, pay, and benefits are available. Even though MEAL was able to provide fringe benefits, retaining staff continues to be a challenge. One lesson learned was not to offer fringe benefits to employees until they have been employed for at least three months. This action has proven to be a valuable cost-saving measure.

- Another lesson is to carefully consider the position of live-in manager. It is an ideal situation for the organization to know that there will always be someone on site to deal with emergencies, but it does have its drawbacks. MEAL's experience has shown that a live-in manager has a very hard time getting time off away from the facility. This can increase the risk of employee burnout. One alternative might be to use staff from other villages in the region on a rotating basis.

- Community commitment is the key to the ongoing success of Marrulut Eniit Assisted Living. The steering

committee made efforts to keep the community informed throughout the development process in order to keep the momentum of interest for the project. Potlucks and teas were held periodically, inviting elders and community members to inform them of the progress. Everyone felt a strong connection to the home even before it opened. Community members continue to volunteer time, talents, and resources, contributing to the fiscal and social health of the facility.

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Guidelines for Discussing Palliative Care and End-of-Life Planning in American Indian/Alaska Native Communities

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Introduction

Palliative care is the **active, total care** of a person when cure is not possible. Palliative care services enhance medical care through emphasis on the relief of physical, psychosocial, and spiritual pain and other symptoms. While palliative approaches should always accompany curative and disease-modifying therapies, as a person nears death, the benefit of potentially curative or disease-modifying therapies decreases and palliative approaches become the focus of efforts. The point in the course of a disease process when individuals and their families recognize the benefits of this change in focus vary (See Figure 1).

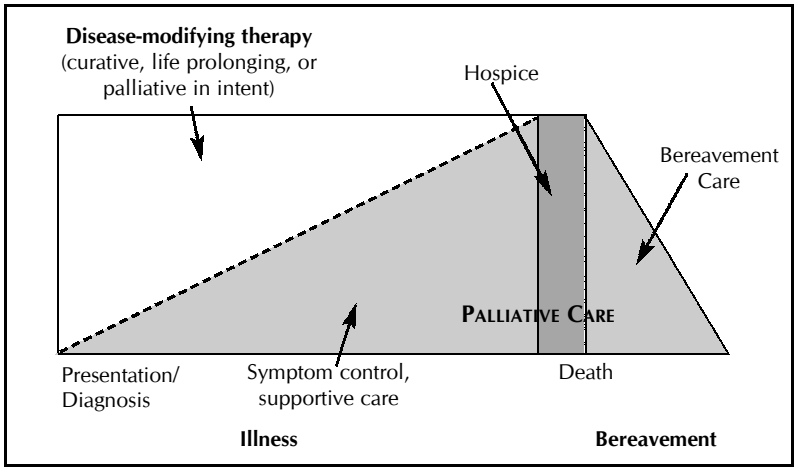
The choice of a palliative care focus can decrease suffering and allow patients and families to achieve meaningful resolution to their lives together. Unfortunately, discussions necessary for end-of-life planning are difficult and frequently are postponed until the patient is close to death, potentially depriving the patient and family of palliative therapies to reduce pain and suffering.

Advanced Directives

The Patient Self-determination Act (PSDA) of 1991 requires all health care institutions that participate in the Medicaid/Medicare programs to inquire upon admission whether patients have advanced directives and, if not, to help them prepare them, if desired. Advanced directives, whether verbal or written, represent the individual wishes for treatment preferences for end-of-life care.

Since the implementation of the PSDA, several broad impact outcomes have become evident. One positive outcome of the PSDA is the open societal discussion of the protection of patient self-determination regarding treatment preferences for end-of-life care, usually involving life-sustaining therapies that may be futile and/or cause prolongation of suffering. Families are questioning the automatic default to, and efficacy of cardiopulmonary resuscitation, prolonged ventilator sup-

Figure 1. The continuum of care from curative to palliative.



port, feeding tubes, and repeated chemotherapy trials, in the face of limited clinical response. However, research documents only a 10-25% national completion rate for advanced directives, usually filled out by those with terminal illness and/or by individuals from higher socioeconomic classes. Even then, physician compliance with advanced directives is poor.[1]

The low completion rate suggests that written advanced directives may not be a useful approach for all populations. The future planning for death forces individuals to accept a temporal orientation to the future, a willingness to discuss death, and the belief that human activity can influence future outcomes, and it minimizes the impact of divine intervention or miracles. The autonomy principle assumes that we can accept and choose the quality of our death long before the inevitability and reality of our dying is apparent. Finally, advanced directives also assume that "patient determined choice" is a viable working reality within the hierarchical, institutionalized western hospital setting.[2]

The Native American Perspective

Although literature exists regarding American Indian and Alaska Native views of death and death rituals, studies addressing end-of-life issues such as advanced directives are rare.[3,4] However, several broad concepts are evident.

Death is a natural and accepted part of the life cycle. The cyclic nature of life and death allows for a harmonious unity concept of a circular view of the human experience. Many American Indians and Alaska Natives believe in some type of existence after death -- a change of worlds, and not a finite ending. Death and dying may not be openly discussed in all tribes, but it is not hidden. Through traditional rituals and stories, children are taught about the naturalness of death. Resolving family matters and preparing for one's death, as a spiritual journey, are valued goals.

Great diversity exists in values, beliefs, and proscribed behavior. In the United States there are over 500 Federally recognized tribal governments. End-of-life planning has been influenced by great variation of traditional beliefs about dying and death, both between and within tribal and cultural groups, as well as the influence of Christianity and the level of acculturation to the majority society. Being knowledgeable about the local belief system does not permit a health care provider to assume the wishes of an individual patient. Any individual might subscribe to some, none, or all of the traditional beliefs in any given situation.

The principle of patient autonomy is respected, coupled with the spirit of consensus and cooperation. The wishes of the individual are highly respected; however, individual autonomy is usually balanced with consensus and cooperation. Over time as the dying process becomes more evident, consensus is achieved by inclusion of extended family, as defined by the patient and elders of the community. Large family meetings, traditional spiritual guidance, and frequent information sessions with health care providers foster the evolution of end-of-life decision-making. There is a willingness to discuss decision-making options verbally, when the "time is right"; however, rarely is it put in writing. The term "Advanced Directives" may be culturally inappropriate, given the belief that one cannot direct one's death in advance; to do so may actually precipitate the death. However, discussions of pain management, relief of suffering, nonabandonment of care, and support of family are appropriate and desired.

When Should Palliative Care or End-Of-Life Planning Be Discussed?

The normative approach to end-of-life decision-making suggests that conversations regarding palliative care or end-of-life care would occur over time at office visits, at home, or in senior centers, when the patient is healthy or feeling relatively well. Palliative care discussions should become a routine part of the care plan for all patients with progressive, chronic illness, and severely ill patients -- even those who have a reasonably good chance of recovery. In order not to frighten the patient, it is important to preface the discussion with a comment regarding the routine nature of this conversation.

> *"I think it is important to talk to all my patients about planning for their future medical care at a time when they are feeling well, so that I can better care for them when they are sick and may be less able to let me know what they might want. I do not have any reason to suspect that your life is currently threatened; however, as you know accidents or illnesses can occur unexpectedly. I would like to understand how you might wish to be treated and who would be the one to make these decisions for you if you were unable to communicate."* [5]

This approach may not be acceptable to those patients and families who live within a cultural framework that proscribes hypothetical discussion of adverse outcomes.

Indications for Such Discussions

Dr. Timothy Quill in *Caring for Patients at the End of Life* recommends the following clinical indications for discussing palliative care:[6]

Absolute Indications

- Patients fear future suffering
- Patients or family members ask about hospice
- Patients are imminently dying
- Patients talk about wanting to die
- Severe suffering and a poor prognosis: any age group

Potential Indications with Severely Ill Patients

- When discussing the patient's hopes and fears
- When discussing prognosis

- Would you be surprised if the patient died in the next six months?

The palliative care conversation might be triggered by clinical situations like the following:

- Repeat hospitalization within a six month period for an exacerbation of a chronic illness (e.g., CHF, COPD, Alzheimer's disease, HIV).
- Patients with a new diagnosis of cancer or with a change in status (e.g. metastatic disease).
- ICU admission with or without mechanical ventilation for exacerbation of chronic illness (e.g., COPD, CHF).
- Status post resuscitation.
- Patients with progressive neurologic disease (e.g., dementia, Parkinson's) and recurrent aspiration or declining nutritional status.
- The frail elder with decline in functional status or repeated hospital admissions.
- Sudden, unexpected injury with poor functional prognosis in any age group
- Children with genetic or chronic noncurable illness with declining functional status.

Components Of Discussions

Research on the most effective manner in which to elicit information on end-of-life planning and patient's preferences is sparse. However, a private setting, a professional interpreter when needed, and uninterrupted time are essential. These discussions require a relatively high cognitive ability in the patient, and strong, emotional reactions such as anger, tears, withdrawal, silence, and walking away may manifest in the short term. However, the long-term psychosocial benefits for the patient and family are demonstrated in the ability to prepare for a peaceful death and in our ability as health care providers to meet the needs of the patient as they understand those needs. Components of these discussions should include:

- Ascertainment of the patient's values/preferences/goals that make life worth living, or intolerable. Open-ended questions can be useful for exploring a patient's concerns, goals, or fears.
  - *"What concerns you most about your illness?"*
  - *"As you think about your illness, what is the best and the worst that might happen?"*
  - *"What are your hopes (expectations, fears) for the future?"*
  - *"What matters most to you?"*
  - *"Some people have clear ideas about treatments that they would want or not want under certain conditions."*
  - *"Some people feel very strongly that they would like to be alive under any circumstances, no matter what, even if they had to breathe with a machine or were unable to walk or speak."*[6]

- Description of actual procedures or treatments in lay terms: cardiopulmonary resuscitation, intubation, intensive care unit care, artificial feeding, and persistent vegetative state.

- Discussion of the benefits and risks of procedures/treatments, and the chances of recovery and at what functional level.
  - In general, one-half of all individuals survive CPR initially, one-third live 24 hours and one in eight survives to leave the hospital.
  - More specifically, for in-hospital arrests, 6-15% of patients survive to hospital discharge; when arrest occurs in a nursing home only 1-2% of patients survive to leave the hospital; and when arrest occurs in the community/home 3-48% survive to hospital discharge.
  - One-third of those discharged after resuscitation have significantly decreased functional status needing nursing home or intensive in-home care, and 2-5% have mental impairment that is irreversible.
  - Survival is worst for those who are older and those with terminal illness.[5]

- Artificial feeding and nutrition is an area of high familial controversy. Both enteral and intravenous feeding mechanisms were designed for short term use, associated with complications and potential increased suffering. Death without artificial feeding is not uncomfortable and artificial feeding may not prolong life and may increase suffering.

- Offer to provide a written summary of the discussions to the patient or written materials on advanced directives.

- Reassurance that as a health care provider you are committed to providing pain and symptom management, and you will be actively focused on the quality of their life.

In conclusion, open-ended questions, following up on the patient's answers by asking questions using the patient's own words, and empathic comments are appropriate. Active listening, empathic communication, and addressing associated emotions have therapeutic value in and of themselves. As patients and their families struggle to find resolution in their lives, health care providers can be assured that palliative care and end-of-life discussions are invaluable in the journey of life.

These guidelines were developed with input from the Indian Health Service "Advanced Directive" Elder Initiative Listserv Group and were presented at the Combined Councils Clinical Conference in San Diego, January 2002. Please send input and comments to Judith Kitzes, MD, MPH, Palliative Care Office, Epidemiology and Cancer Control, CRTC/UNM,

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Arthritis Care and Beliefs in an Urban American Indian Population

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Arthritis joint pain is a concern of aging Americans and a leading cause of disability in the United States. American Indians are more likely than other Americans to suffer from arthritis pain. Higher prevalence rates of inflammatory arthritides in American Indian populations have been documented for rheumatoid arthritis,[1-5] systemic lupus erythematosus,[3,6-7] and scleroderma.[8] In a recent national study American Indians reported significantly more frequent pain experiences than other Americans,[9] and arthritis was the greatest predictor of that pain.[10]

Cultural interpretations can impact treatment decisions and self-care of chronic disease. For instance, Tlingit who have been diagnosed with an inflammatory arthritis may understate their level of disability as a culturally appropriate response to inquiry about functional impairment.[11] Canadian First Nations peoples generally delayed their entry into the healthcare system until more severe symptoms are manifested.[12]

People's beliefs about chronic joint pain and self-care practices were the subject of a study conducted in pan-tribal urban Los Angeles and Orange Counties, California.[13-14] American Indian project staff conducted in-depth interviews with a small convenience sample of American Indian community members who experience chronic joint pain. These respondents, recruited by American Indian community organizations, suffered from inflammatory (mean age 54.0 years) and non-inflammatory (mean age 59.4 years) arthritis joint diseases. Those with inflammatory arthritis had more swollen (10.9±11.7) and tender (17.8±11.9) joints than those with non-inflammatory arthritis (1.4±2.0; 4.4±4.1, respectively). However there was no significant difference in the mean level of pain intensity between these two groups.

Individuals who experience chronic joint pain generally sought medical care for persistent and/or multiple joint pains. Their reasons for seeking care were a similar strong belief that pain was not normal at any age. Unlike the general population, they did not confound arthritis with a normal aging process; as quite a few respondents noted, "aging doesn't hurt." In fact, most did not assume at first that their pain was caused by arthritis.

Seeking health care did not necessarily lead to prescribed pharmacotherapies for the management of disease activity in inflammatory arthritis. Drug therapies were prescribed for pain relief only for the most severe symptoms of inflammatory arthritis, while severity of non-inflammatory arthritis symptoms did not predict prescription of medication to reduce painful symptoms. Rarely were these respondents offered other treatment strategies, such as education about nonpharmacologic approaches to improve function, protect joints during activity or reduce joint pain with localized specific therapies.

Nonsteroidal anti-inflammatory drugs (NSAIDs) were commonly used in subtherapeutic doses for daily and/or intense joint pain episodes in persons with chronic arthritis. Even a decade after onset, these persons continue to experience moderate pain on a regular basis. Instead of medication or localized therapies, they most frequently endured the discomfort of their chronic pain and episodic flares or ignored their painful symptoms. While these strategies have been associated with better pain control, better function, and less depression in other populations,[15-16] use of these strategies also highlights the subtlety that might be expected in communications related to pain.

Despite seeking medical care for chronic joint pain, many persons commented on how difficult it is to ask for help, discuss pain, or disclose the intensity of a painful episode. Typical statements included:

- "We don't feel comfortable talking about ourselves and usually don't let people know our pain."
- "Indians are independent, shy and won't ask for help."
- "Indians don't complain of aches and pain."
- "If someone says it hurts a little, [they are] probably underplaying the level of pain."
- "A Native American who suffers from pain is a very needy patient."

One respondent delineated the key to a productive clinical physician-patient relationship as, "Doctors need to be aggressive but friendly to dig out problems." If a pain complaint, once divulged to a physician, is not addressed, the complaint will not be voiced again "unless they are really bad off."

We asked how respondents described their joint pain in general, and specifically to their doctors and to their families. A pattern emerged of common English-language descriptive terms that expressed the sensations of joint pain: one set of descriptors was used for inflammatory joint pain and another was used for non-inflammatory joint pain (see Table 1). These terms were specific to both disease and level of pain. However, a third set of descriptors also emerged (see Table 2). These vague, general pain descriptors were used for any type of joint pain and were not related to pain intensity. For instance, "ache," "pain," and "discomfort" could describe either the lowest or the highest intensity of pain.

Table 1. Arthritis disease-specific descriptions of joint pain according to pain intensity: comparing inflammatory arthritis and noninflammatory arthritis descriptors using a visual analog scale (VAS)

Disease Catagory	Pain Intensity			
	Mild VAS 1-3	Moderate VAS 4-6	Severe VAS 7-9	Worst VAS 10
Inflammatory Arthritis Joint Disease	Heat penetrating skin Like little burn Mushy Numb Puffy Sore Steady Stiff **Swollen** Tender Tight **Throbbing**	Bones got fat inside Like pliers squeezing Pretty bad Sensitive to touch **Swollen** **Throbbing**	Inside of knee is growing No control Sharp, intense Stretched to pieces Throbbing	
Non-Inflammatory Arthritis Joint Disease	Feels hard in there Tired	Aggravating Annoying Bothers me/ Bothering Can't work like used to Like got hit Like muscle spasm **Like toothache** Pulling Twinges **Severe** **Stabbing**	Can't move Hated (limitation) **Like constant toothache** Like beating on drum Tiring **Severe** **Stabbing**	Cuss words Horrible **Severe** Terrible Unbearable

Note: Bold font indicates terms that are used for more than one level of pain intensity.

Table 2. Vague general verbal descriptions of inflammatory and non-inflammatory arthritis joint pain and self-report of pain as measured with a visual analog scale (VAS)

Mild and Moderate Pain VAS 1 - 6	Severe and Worst Pain VAS 7 - 10
Aches Constant (or won't go away) Discomforting Dull pain Gnawing Hot Hurts/hurtful Locks up * Mild pain Moderate pain** Pain/painful Sharp pain Uncomfortable	Aches Constant (or won't go away) Discomforting Excruciating*** Gnawing HotHurts Pain/Painful Sharp pain Uncomfortable

Bold text indicates descriptors used for mild/moderate and severe/worst pain
* Describes VAS 1 - 3 only
** Describes VAS 4-6 only
***Describes VAS 10 only

Conclusions

American Indians in this urban sample made a clear distinction between chronic pain and the expected aches and pains that result from living a full and active life. They do not consider chronic joint pain to be normal at any age. As a result, most American Indians consulted physicians after the nature of pain had become chronic in multiple joints, and self-care options had failed. Nevertheless, the severity and impact of chronic arthritis was generally under-recognized and under-treated in this population. This is of particular concern for an inflammatory disease, such as rheumatoid arthritis, in which early recognition and aggressive treatment are related to improved prognosis.

In conducting a cultural assessment, clinicians should be aware that American Indian patients do not emphasize pain complaints. Culturally appropriate expressions of painful symptoms are subtle and might, in fact, reflect symptoms of a more serious nature, such as rheumatoid arthritis. Therefore a request for medical care for chronic joint pain should be taken seriously, clinically evaluated and, if warranted, referred to a rheumatologist for arthritis care. In this urban population, enduring or ignoring pain was the most common coping strategy. Nevertheless most respondents were interested in learning more about arthritis, disease management and effective pain relief strategies. Our next step will be a community-based education intervention based on the Arthritis Self-Management Program, a standardized 6-week course of community-based education using a behavioral approach, which has been shown to have a positive impact on health behaviors, health status and healthcare utilization. □

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Osteoporosis in Native Americans

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Introduction

In the United States (U.S.) medical, psychosocial, and economic burdens associated with osteoporotic fractures are increasing.[1] The impact of osteoporosis and its complications is largely unknown among Native Americans.[2,3,4] The Healthy People 2010 objectives include the following: to reduce the overall number of adults who are hospitalized for vertebral fracture associated with osteoporosis; however, data from national surveys used to develop these objectives were statistically unreliable for Native Americans. Bone mineral density (BMD) categories proposed by the World Health Organization (WHO) for diagnosis of osteoporosis are based on mean BMD values of young, Caucasian adult women, and uncertainty exists about the accuracy of diagnosis among children, men, and women of other race/ethnic groups.[5]

According to the 2000 Census, there are 2,475,946 American Indians and Alaska Natives (AI/AN) living in the U.S. Twenty four percent are 45 years and older, of which 53% are female.[6] Information about osteoporosis risk factors and prevalence for AI/AN is scarce, and the limited data available show that the prevalence of those risk factors vary among different AI/AN groups. The purpose of this paper is to review the literature concerning the occurrence of osteoporosis (based on BMD levels), osteoporosis complications (fracture), major risk factors (calcium, vitamin D, physical activity, menopause/aging, body mass index, and smoking) and prevention strategies (hormone replacement therapy use) among AI/AN. The broader term "Native American" may be used to

include American Indians, Alaska Natives (Eskimos, Inuits, and Indians), Canadian Indian (Oneida, Chippewa, Muncey, and Dene/Métis) and Mexican Mayans. Topics throughout the paper will be organized into regional divisions or cultural areas when there are enough data. These divisions represent some similarities in practices and activities of the societies who live there, but they should not be mistaken as identical. The divided regions will include Northeast, Southeast, Plains, Great Basin, Southwest, California, Northwest coast, Subarctic, and Arctic.

Osteoporosis Assessment and Complications

BMD. The WHO has set up criteria using BMD to diagnose osteoporosis.[8] Low BMD, among Caucasian women, is a strong risk factor for fracture.[1] Among Native Americans very little is known about BMD. Three studies reported BMD decreases with age in Native American women using radiography,[9] single photon absorptiometry (SPA),[10] and dual energy X-ray absorptiometry (DXA).[11] Studies have reported significantly lower BMD in postmenopausal Native American women,[9,12] but higher BMD in premenopausal Native American women,[11] compared to Caucasian women in the same age group. Small sample size and cross-sectional design were limitations of these studies, and because different skeletal sites were measured, comparisons between studies are impossible.

Fracture. The prevalence of osteoporotic fractures among Native Americans is inadequately reported. One study stated the prevalence of hip fracture was 80% higher in Canadian Indian women compared to non-Canadian Indian women 55 and older. Canadian Indian men, in the same age range, reportedly had fracture rates similar to non-Canadian Indian women.[4] Among Mayan elderly women, prevalence of fracture was low.[10] Alaskan Eskimo women, according to non-published data, had twice the incidence of hip fracture as Caucasian U.S. women during the period 1979 to 1985; however, Eskimo men had lower incidence of hip fracture compared to Caucasian U.S. men.[13] Diagnoses of hip fracture and other sequelae of osteoporosis were rare among the IHS Navajo Area user population, during the period 1992-1994, based on the Navajo Health and Nutrition Survey, despite investigators finding a low calcium intake among the study population.[14] These observations suggest that different Native American groups are at different levels of risk for fracture. Nevertheless, without fracture studies reporting BMD and other possible risk factors, it is unclear whether the fractures reported are related to low BMD, or high risk activities. Risk factors for fractures, besides low bone mass, are increased risk of fall due to age, qualitative changes in bone structure, and variability in bone geometry.[15] Native Americans may have a great variability in bone thickness.[16] Currently, with the general lack of data, it is impossible to assess if osteoporotic fracture is a significant problem among Native Americans.

Osteoporosis Risk Factors

Calcium Intake and Vitamin D. Calcium is critical for bone health. Calcium intake has been documented for Native American populations in the Subarctic and Arctic, Southeast, Plains, and Southwest (Table 1 - see page 96). The intakes reported are from dietary sources; calcium supplement use was not found. The U.S. National Academy of Sciences recommends calcium intake for different age groups as follows: 9-18 years: 1300mg/day; 19-50 years: 1000mg/day; and 51+ years: 1200mg/day.[17] Canadian Recommended Nutrients Intake (RNI) for calcium is 700-800mg/day for 18 years and older.[18] A study[27] among Dene/Métis in Canada reported calcium intakes of 412-564 mg/day for males and 478-550 mg/day for females, much lower than the recommended levels. Comparing results from earlier U.S. studies in Native Americans[13,22,24,26] to the Second National Health and Nutritional Examination Survey, NHANES II, calcium intake in Native Americans was below the average range (561-679mg) among females age 20 to 60 in the United States. Later U.S. Native American studies,[14,21,23,25] when compared to the NHANES III, also showed that Native American intake was below the average intake range (626-778mg) for females 20 and over. The large amount of lactose intolerance reported among Native Americans[14,19,20] is one possible reason for the low intake among this ethnic group.

All studies were cross-sectional and the variation in sample sizes, collection times, ages, and nutrient intake analysis make it impossible to compare across groups. Sample selection methods ranged from no discussion of methods,[20,21,22,23,24] to convenience sample,[19] random sample,[25,26,27] and systematic sample[13,14] (i.e., choosing every 10th house, 3-stage cluster design). The use of randomized or systematic methods is preferred in order to obtain a representative sample of the population. Different databases were used to calculate nutrient intakes. Most studies reported that traditional foods were incorporated into the nutrient analysis,[13,14,18,21,23] but only a few mentioned if the instruments had been pre-tested for the population.[20,22,25,26] Trained interviewers and food models, which increase the validity of dietary surveys, were used in almost all the studies.[13,14,18,20,21,23,25]

In summary, the crude comparison between the reported calcium intake in Native Americans and the NHANES average ranges show that Native Americans have lower calcium intake than the U.S. population, and the U.S. population is not meeting the recommended dietary calcium intake levels. Without studies that look at BMD and calcium in the same Native American communities, using validated instruments, and incorporating analysis of traditional foods, no direct assessment of this risk factor can be done.

Vitamin D has direct and indirect effects on bone. Reduction in vitamin D levels may reduce the absorption of calcium. Research done on vitamin D and Native Americans is relatively non-existent, especially among the elderly. Only one study discussed dietary vitamin D among Native

Table 1. Reported dietary calcium intake among various Native American populations

Author (year)	Instrument	Population (division)	N	Mean age (age range)	Gender	Ca (mg/day) mean (range)/median
Bass & Wakefield (1974)[22]	24-hour recall	Standing Rock Sioux (plains)	94	NA (19-75)	Females	406(NA)/NA
Betts & Crase (1986)[19]	3-day diet record	Urban Indians in Nebraska Omaha (plains) Sioux (plains)	20	65.7 (50-75+)	Males &Females	506.88 (NA)/NA
Harland et al. (1992)[24]	FFQ	Waccamaw Siouan (southeast)	Total= 56 35 21	NA (18-87)	 Males Females	 708(NA)/NA 476(NA)/NA
Nobmann et al. (1992)[13]	24-hour recall	Alaska Native (northwest/subarctic and arctic)	351	NA (21-63)	Males Females	689(NA)/NA 516(NA)/NA
Brown & Brenton (1994)[20]	3-day diet records	Hopi (southwest)	96	11.4 (10-13)	Males & Females	874 (236-1,652)/NA
Bell et al. (1995)[26]	3-day diet record	Lumbee (southeast)	107	37.9 (21-60)	Females	466 (NA)/NA
Smith et al. (1996)[21]	24-hour recall	Pima (southwest)	575	NA (18-74)	Males Females	905(NA)/NA 802(NA)/NA
Ballew et al. (1997)[14]	24-hour recall	Navajo (southwest)	Total = 946 89 73 157 225 77 163 67 95	NA (12-60+) 12-19 20-39 40-59 60+	 Males Females Males Females Males Females Males Females	 876(NA)/587 637(NA)/544 560(NA)/438 483(NA)/372 447(NA)/345 378(NA)/310 402(NA)/311 386(NA)/315
Receveur et al. (1997)[27]	24-hour recall	Dene/Métis (subarctic and arctic)	Total = 1012 Summer=356 Fall=656	NA (20-61+) 20-40 41-60 61+ 20-40 41-60 61+	 Males Females Males Females Males Females Males Females Males Females Males Females	 547(NA)/NA 550(NA)/NA 519(NA)/NA 526(NA)/NA 492(NA)/NA 548(NA)/NA 564(NA)/NA 526(NA)/NA 544(NA)/NA 526(NA)/NA 412(NA)/NA 478(NA)/NA
Vaughan et al. (1997)[23]	24-hour recall	Havasupai (southwest)	Total =92 23 9 50 10	 Young = 35 (18-59) Old =79 (60-99) Young = 34 (18-59) Old = 72 (60-99)	 Males Males Females Females	 651(NA)/602 599(NA)/599 651(NA)/544 575(NA)/461
DeGonzague et al. (1999)[25]	24-hour recall	Ojibwe (subarctic and arctic)	Total = 104 44 56	NA (20-61+)	 Males Females	 762(NA)/NA 480(NA)/NA

Americans. Smith et al[21] reported among Pima Indians vitamin D intake increased with age, and large proportions (62%-36%) had intakes below two-thirds the recommended levels, but concluded that risk of deficiency was low, due to desert sun exposure. Differences in vitamin D sufficiency relate to sunlight exposure, season, latitude, pollution, clothing, skin pigment, age, and kidney function.[28] All of these factors vary depending on the population, and studies among different Native American communities are needed to assess vitamin D levels. Specifically, assessing calcium and vitamin D among groups like the Canadian Indian community, who had higher incidence of fractures,[4] will aid in understanding diversity among Native American groups.

Physical Activity. Sedentary lifestyle is associated with low BMD. No physical activity, defined in a variety of ways for both males and females, ranged from 18% to 60% among the different Native American communities (Table 2). The 1997 Behavioral Risk Factor Surveillance System (BRFSS) and the U.S. Women's Determinants study reported Native Americans participate in little or no leisure time (exercise, recreation, or physical activities such as running, calisthenics, golfing, gardening, or walking that are not performed as part of regular job duties) or regular (participation in leisure-time physical activity) physical activity.[29,30] The prevalence of no physical activity during leisure time (no participation in 24 common activities such as gardening, walking, hunting, dancing, or sports) in the Strong Heart study, which assessed North and South Dakota, Southeastern Oklahoma, and Arizona Native Americans, ranged from 32% to 60%.

A study among Chippewa and Menominee reported 33% and 21% of women and men participated in no physical activity during leisure time (no exercise or sports such as running, gardening, or wood chopping for exercise or pleasure).[32] Urban Ojibwe and Sioux women living in Minneapolis increased in participation from strenuous to mild exercise.[33] Sixty percent and 56% of Native American women and men living on or near reservations in Montana were not physically active (no exercise, recreation, or physical activities such as

Table 2. Percentage of Native Americans partaking of physical activity

Author (year)	Population	Sex (N)	Age-range (years)	Definition of Activity	Percentage (95% CI)
Mendlein et al. (1997)[37]	Navajo (southwest)	Female (483) (225) (163) (95) Male (390) (157) (77) (67)	 20-39 40-59 60+ 20-39 40-59 60+	No physical activity/ exercise during the previous month	 28%(NA) 32%(NA) 29%(NA) 18%(NA) 21%(NA) 23%(NA)
Nelson et al. (1997)[34]	Native Americans in Montana	Female(136) Male(108)	 18-29 30-39 40-49	Not physically active (no participation in physical activity for ≥20 mins ≥3 times per week in past month)	59.6%(NA) 55.6%(NA) 52.6%(NA) 59.8%(NA) 60.6%(NA)
Yurgalevitch et al. (1998)[31]	Native Americans of N/S Dakota, Oklahoma, Arizona N/S Dakota Oklahoma Arizona	Female (2703) (864) (885) (954) Male(1846) (658) (642) (546)	45-74	No leisure physical activity in the past week	 40%(NA) 42%(NA) 60%(NA) 32%(NA) 32%(NA) 53%(NA)
Fischer et al. (1999)[32]	Chippewa and Menominee (northeast)	Females Males (1344)	25-65+	No leisure time physical activity during the past year for at least 12 times	33%(NA) 20.8%(NA)
Risendal et al. (1999)[36]	Southwest Native Americans - mainly Pima and Pascua Yaqui	Female (519) (186) (165) (79) (89)	 <30 30-39 40-49 ≤50	No regular physical activity reported (2 to 3 times a week for 20 mins per session)	 24.7%(NA) 33.3%(NA) 32.9%(NA) 52.8%(NA)
Brownson et al. (2000)[30]	Native Americans	Female (738)	40-70+	No leisure time physical activity durin the past 2 weeks	48.7% (45%, 52.4%)

running, calisthenics, golfing, gardening, or walking).[34] Forty-eight percent of adult Lakota Indians reported "sometimes" engaging in heart rate-increasing activity.[33] Among Southwest Native Americans, no physical activity ranged from 10% (no walking outside the home for more than 10 minutes without stopping or other physical activity that worked up a sweat, hard breathing, or fast heart rate)[36] to 30% (no participation in any physical activity or exercise such as running, basketball, softball, aerobics, walking, hunting, getting wood, swimming, or other activities for exercise).[37]

Overall, physical activity levels are low; possible reasons include barriers to participation and the complexity of assessing physical activity with questionnaires. Studies varied in types of questionnaires, definitions of physical activity, age groups, and sample sizes. Major limitations include using only telephone surveys and only administering questionnaires in English; and adding bias by excluding those without telephones and more traditional families or communities. More studies are needed among individual Native American groups using random samples, larger sample sizes for different age groups, face-to-face interviews with community-based, trained interviewers, and community validated questionnaires, in order to have a clearer picture to relate to osteoporosis risk assessments.

Menopause. Estrogen deficiency due to menopause, either natural or surgical, is associated with bone loss. Among Caucasian women, menopause before age 40, surgical or natural, or conditions (anorexia nervosa, exercise-induced amenorrhea) that interfere with normal menstruation are associated with osteoporosis.[38] Average age at menopause for the U.S. population is 50.[3] Only two studies looked at age of menopause in Native Americans. Among Mayan women, menopause typically occurred at 44.4 ± 7.3 years.[10] This cross-sectional study used a convenience sample of 118 women. The mean age of menopause for Blackfeet women living on the reservation in Montana was 51.2 ± 5 years; within the range, 50-51.3 years, reported from national U.S. surveys.[39] One hundred fifty randomly selected women agreed to participate; 70 of them reported being menopausal. Age at menopause for both studies was based on recall, which presents problems since it relies on memory, and women have different ideas about when menopause starts across cultures. The convenience sample was larger; however a random recruitment method is preferred since it is more representative. Studies are vitally needed to better understand the menopausal experience of Native Americans.

Body Mass Index. Low BMI (<19 kg/m^2) is a risk factor for osteoporosis. BMI values varied among Native American groups, and most had large proportions of overweight or obese individuals (Table 3). The 1985-1996 BRFSS[40] and the National Medical Expenditure Survey[41] reported 24% to 45% of Native American men and 23% to 46% of Native American women were overweight (BMI ≥27.8 for men and BMI ≥27.3 for women). Smaller individual Native American group studies have reported at least a quarter[19,24,25,42,43] or half[21,22,23,32,33,37,43,44,45,46,47,48] of the studied population were overweight by various criteria (BMI ≥27.8 for men and BMI ≥27.3 for women, BMI ≥26, self-perceived overweight, 20% or more above ideal weight for height , BMI ≥25, BMI ≥27).

Differences in the classification of obesity, sampling methods, sample size, and age groups make it impossible to compare BMI levels among Native American groups. Only one study looked at the relationship of weight and BMD in Native American women. Chen et al[12] found weight and BMI to be significant predictors of BMD in Southwest Native American women. More studies are needed to look at the impact of obesity on BMD and fracture risk among the Native American population.

Smoking. Among Caucasian women, current and past smoking is associated with lower BMD. Native Americans have a high prevalence of smoking.[49] According to the 1995-1998 BRFSS,[50] 44.5% of Plains Native Americans, 39.9% of Alaskan Natives, 31.9% of Eastern (both north and south) Native Americans, 28% of Northwest Native Americans, and 21.5% among the Southwest Native Americans were current smokers. Welty et al[51] reported 40% of Native American men and 30% of Native American women were current smokers in the Strong Heart Study. The largest percentage of current smokers, 53% for men and 45% for women, were from the North/South Dakota region. Percentages for Arizona and Oklahoma were 30% and 37% for men and 13% and 32% for women. Kaplan et al,[52] after reviewing published and unpublished reports from national, state, and local surveys on smoking from 1987 to 1993, reported that among Alaska Natives, smoking prevalence ranged from 39% to 50%.

Smoking prevalence among individual Native American groups was reported for the Northwest, Southeast, Northeast, and Plains regions. Forty three percent of men and 54% of women among Native Americans in Washington State reported being current smokers.[53] Among Lumbee women, 39% were current smokers.[54] Peterson et al[45] found among the Chippewa Tribe living in Wisconsin, 88% of males reported ever smoking and 69% were current smokers; females reported 78% and 63%. Current smoking prevalence, according to the 1999 BRFSS, among Native American males and females in Montana was 42%.[55] Chippewa and Menominee Indians had a current smoking prevalence of 55% for both men and women age 25 and older.[32] Among Blackfeet women, 36.4% were current smokers and 66.7% were ever smokers.[39]

Smoking was also reported among Southwestern and California regions. Giuliano et al[48] looked at smoking prevalence among Hopi women. The percentage of "ever-smoked" was 17.6% and "current smoker" was 5.4%. In the Navajo Health and Nutrition Survey, 16% of men and 5% of women were reported as current smokers.[37] Risendal et al[36] assessed smoking among urban Southwestern Native American women. Twenty percent reported being a current smoker. Native American men and women in rural New Mexico reported 38%

Table 3. Percentage overweight/obese in Native Americans

Author (date)	Population (division)	N	Sex	%Overweight or Obese
Will et al. (1999)[40]	Native Americans (NA)	4490	Males/Females	24.4-45.3/23.2-46.4[a]
Broussard et al. (1991)[41]	Native Americans (NA)	3200	Males/Females	33.7/40.3[a]
Young & Sevenuysen (1989)[42]	Cree, Ojibwe (subarctic and arctic)	704	Males/Females	20-77/40-88[c]
DeGonzague et al. (1999)[25]	Ojibwe (subarctic and arctic)	104	Males/Females	49/43[a]
Katzmarzyk & Malina (1998)[44]	Canadians of First Nation (subarctic and arctic)	80	Males/Females	51/60[a]
Murphy et al. (1995)[43]	Eskimo, Athabascan Indian (subarctic and arctic	1124	Males/Females	27, 25/51, 39[a]
Peterson et al. (1994)[45]	Chippewa (northeast)	175	Males & Females	54[a]
Harnack et al. (1999)[33]	Urban Native Americans mainly Ojibwe (subarctic and arctic) and Sioux (plains	203	Males & Females	66[a]
Fischer et al. (1997)[32]	Chippewa (northeast) and Menominee (northeast)	1344	Males/Females	60/68[a]
Bass & Wakefield (1974)[22]	Standing rock Sioux (plains)	94	Females	61[c]
Betts & Crase (1986)[19]	Urban Native Americans mainly Omaha (plains) and Sioux (plains)	20	Males & Females	32[d]
Harland et al. (1992)[35]	Waccamaw Siouan (southeast)	56	Males/Females	11/33[d]
Harnack et al. (1999)[35]	Lakota (plains)	219	Males & Females	55.5[a]
Costacou et al. (2000)[46]	Catawba (southeast)	644	Males & Females	63[e]
Smith et al. (1996)[21]	Pima (southwest)	575	Males/Females	58-72/82-87[a]
Knowler et al. (1991)[47]	Pima, Tohono O'odham, Maricopa (southwest)	379	Males/Females	31-78/48-87[a]
Vaughan et al. (1997)[23]	Havasupai (southwest)	92	Males & Females	80[f]
Mendlein et al. (1997)[37]	Navajo (southwest)	788	Males/Females	35/62[a]
Giuliano et al. (1998)[48]	Hopi (southwest)	559	Females	63[a]

[a] BMI >27,8 for men and BMI >27.3 for women
[b] BMI >26
[c] Self-perceived overweight
[d] 20% or more above ideal weight for height
[e] BMI >25
[f] BMI >27

were ever smokers and 17% were current smokers.[56] Among the Pascua Yaqui, 43% of men and 24% of women were current smokers.[57] One study[58] reported that 39.9% of Native Americans, men and women, in Northern California were current smokers.

In general, the individual group studies, which were mostly done using face-to-face interviews with randomly selected participants, agreed with the general conclusions drawn from the BRFSS results; current smoking prevalence was high among all Native American groups in U.S. Native American groups in the eastern half of the U.S and Alaska seem to have higher smoking rates than the western groups, and the reasons why are not clear. These data were self-reported, and inherent with smoking or any perceived "bad" behaviors, true values are usually higher. While smoking is associated with lower BMD in the general population the relationship between smoking and BMD needs to be looked at especially among Eastern and Alaskan Native American groups, who seem to have a higher prevalence of smoking.

Preventing and Managing Osteoporosis

Estrogen protects against bone loss, and hormone replacement therapy (HRT) has been shown to increase bone mass by 5% to 10% in Caucasian women who start it early.[59] HRT use among Native Americans is unclear because few studies have reported data on it. The Strong Heart Study reported current estrogen use ranged from 5% in Arizona to 21% in Oklahoma.[60] Perry et al[11] reported that 7% of the women from the Sac and Fox nation used HRT. Native women, mostly Southwestern Native Americans, participating in the Women's Health Initiative at baseline reported 44%.[12]

A qualitative study of minority women's, including Navajo women, experiences discussed personal views on HRT.[61] Navajo women reported that many of them were not

aware of HRT and felt their doctors did not explain it. Women who had taken HRT reported dissatisfaction due to its side effects. More studies need to look at HRT use among Native Americans in relation to BMD to assess its effects on bone mass.

Summary and Recommendations

Most of the studies reviewed for this paper were cross-sectional, and prospective studies, while ideal, are challenging and often not feasible. However, differences in BMD, aging, and other osteoporosis risk factors may be due to regional variation, and longitudinal studies are needed to assess this issue. Overall, there is a general lack of information about osteoporosis risk factors among Northeast, Great Basin, Northwest, and California Native Americans, especially for menopause, vitamin D, and HRT use. All osteoporosis risk factors discussed in this paper are contributors within the Caucasian population, but no studies have looked at them among Native Americans in relation to osteoporosis. Thus there is no way to know now how they contribute to the development of osteoporosis in this population. The prevalence of osteoporosis and osteoporotic fractures among Native Americans is unknown. Using diagnostic criteria developed from studies of Caucasian women is questionable, and needs to be further investigated. □

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Nine Questions To Ask Yourself About Elder Care In Your Community

Bruce Finke, MD, Coordinator, IHS Elder Care Initiative, Zuni, New Mexico

1. Preventive care

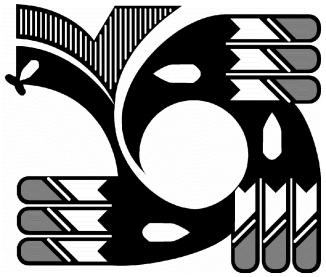
Are we providing our elders with the opportunities they deserve to remain strong, healthy, and independent?

Offer elders a well elder visit once a year. This gives you an opportunity to assess functional status; screen for depression, cognitive impairment, elder abuse or neglect, and fall risk; and offer preventive screening tests. It is also an opportunity to assess the ongoing management of chronic disease (and this is reimbursable by third party payers). Use the PCC Comprehensive Elder Exam (IHS 865) available through the usual forms ordering process and on PCC+. You will find information about using and ordering the PCC Comprehensive Elder Exam on the Elder Care Initiative website.

2. Focus on Function

Do we know how well our elders are doing, not just what diseases they have?

Functional assessment, the characterization of the ability to do activities of daily living (ADLs) and instrumental activities of daily living (IADLs), is an essential part of quality care of the elderly. These data can now be entered into RPMS and printed on the health summary. It should be readily available and current in the medical record of every elder. Once again, the PCC Comprehensive Elder Exam can help you to do this.



3. Long-Term Care

What are the long-term care resources in my community and how well are we supporting families caring for frail elders in the home?

"Long-term care is a set of health, personal care, and social services delivered over a sustained period of time to persons who have lost or never acquired some degree of functional capacity." (R. A. Kane & R. L. Kane. Long-term care: Principles, programs, and policies. New York, NY: Springer, 1987).

The family provides the majority of long-term care for elders. They need support, education, and access to professionals for information and advice. The majority of formal long-term care services are paid for by Medicaid and state home and community based care programs. In many cases these services can be provided through tribal health programs, but the formal home and community based care infrastructure in Indian Country is not well developed. Know your resources and be a part of developing long-term care services in your community. IHS and tribal health programs have a clear role to play in assessment, case management, and helping to coordinate the often fragmented long-term care services for frail elders in the home.

4. Geriatric Assessment

Do we have a mechanism in place to provide a comprehensive assessment of elders, in the clinic or in the community?

Geriatric assessment consists of the evaluation of the elder in multiple dimensions. The goal of a good assessment is to understand the elder's life and what we can do as health care providers to help them function to their fullest capability with a feeling of health. Multiple models of geriatric assessment are available. Geriatric assessment can be done in the clinic by an interdisciplinary team or by an individual provider. It can be a community outreach effort, guided by public health nursing, CHRs, or Senior Center staff. Assessment of the frail elder is the key to the rational and cost-effective allocation of long-term care services. Assessment of the well elder is the key to providing appropriate preventive health measures.

There are still copies of the Guide to Comprehensive Geriatric Assessment in Indian Country available through the

Elder Care Initiative office. This guide provides background information on the process and examples of models developed in the Indian health system. A second edition, with more models, will be produced in the coming year.

5. Palliative Care and Care at End of Life

Are we providing compassionate and competent care to those who medicine cannot cure?

Good palliative care does not occur by accident. We need to have the training and skill to know what to do, and we need to adjust our systems of care so that we can do what we know how to do. This requires teamwork and planning. We are not providing quality care to our elders unless we can care well for them through the very end of their lives.

6. Knowledge Base

Does our staff have the knowledge base needed to provide high quality care to our elders?

Elders are different; they are not just "older adults." Set up an ongoing program of continuing education on geriatric topics (including palliative care) in your facility, and target some of your outside training toward geriatric topics. The New Mexico Geriatric Education Center (in collaboration with the IHS Elder Care Initiative) offers a yearly Geriatric Summer Institute in Albuquerque that focuses on care of AI/AN elders. The National Resource Center on Native American Aging (NRCNAA) in North Dakota is hosting a weeklong intensive geriatric training for Indian health professionals in Minneapolis this June. The IHS is holding intensive team training in palliative care this month. These and other trainings are free or discounted for Indian health providers. Future training opportunities will be published in the pages of The Provider and on the Elder Care Initiative website.

Copies of the 2000 Geriatrics At Your Fingertips clinical handbook are still available through the IHS Elder Care Initiative at no charge for Indian health facilities and providers.

7. Focus on Quality of Care

Are we looking at elder-specific outcomes in our program improvement efforts?

Adopt local standards of care for key geriatric issues. These can be linked to GPRA outcome measures (e.g., pneumovax administration, elder abuse screening, mammography). Some other potential measures include:

- Well elder exam offered within the past 18 months
- Current functional status available for all elders and noted on all hospital admissions
- Avoidance of certain contraindicated medications in elders (e.g., amitriptyline, long-acting benzodiazepines)
- Treatment of systolic hypertension
- Initiation of a fall prevention program (the American Geriatrics Society Fall Prevention Guidelines are an excellent, easy to implement, evidence-based approach to fall and injury prevention).

8. Resources

Do we know where to look or who to call if we have questions about elder care; either clinical questions or questions about program development?

- IHS Elder Care Initiative: *www.ihs.gov/Medical Programs/ElderCare*
- National Indian Council on Aging (NICOA): *www.nicoa.org*
- National Resource Center on Native American Aging (NRCNAA): *www.und.nodak.edu/dept/nrcnaa*
- Native Elder Health Resource Center (NEHRC): *www.uchsc.edu/ai/nehcr*c
- American Geriatrics Society (AGS): *www.americangeriatrics.org*
- American Society on Aging (ASA): www.asaging.org
- Gerontological Society of America (GSA): *www.geron.org*
- Alzheimer's Association: *www.alz.org*
- AARP: *www.aarp.org*

9. Networking

Am I in contact with the hundreds of others both in and outside the Indian health system who are signed on to the Eldercare listserv?

The Eldercare listserv allows us to share information, resources, and ideas. To sign on send e-mail to: *listserver@hqt.ihs.gov* with the following message in plain text in the body (not the subject line) of the e-mail:

subscribe eldercare yourfirstname yourlastname

After you've subscribed, you can communicate with other participants in the listserv group. Address the email to: *eldercare@hqt.ihs.gov* □

Priorities in Research for AI/AN Elders

A Snapshot from the 13th Annual IHS Research Conference

Bruce Finke, MD, Coordinator, IHS Elder Care Initiative, Zuni, New Mexico

In April 2001, the 13th Annual IHS Research Conference in Albuquerque, New Mexico dedicated its theme day to issues involving research serving American Indian and Alaska Native elders. At that meeting participants were asked to self-select into one of four groups identified as stakeholders in research for AI/AN elders. The stakeholder groups were:

- Elders and their family members
- Direct service providers for the elderly
- Advocates, program planners, and tribal leaders
- Researchers

The underlying premise was that each of these groups had a stake in the process of research in AI/AN aging, as a producer or consumer of the information obtained by the research effort, and often as partners in the process itself. In focus group sessions, each of these stakeholder groups was asked to answer the following question, designed to elicit priority areas for research:

> "What are the key questions that we need answers to in order to improve the well being of native elders?"

Elders' priorities for research (ranked in order of frequency of response):

- Long-term care, nursing home, home health care
- Diabetes
- Day care
- Funding
- Cancer
- Dialysis
- Health education, communication
- Vision impairment
- Cultural competence
- Heart disease
- Medications

Service provider's priorities for research (ranked in order of frequency of response):

- Traditional healing, non-monetary and monetary support of traditional healers, tradition and spirituality
- Culturally valid assessment tools, culturally appropriate evaluations
- End-of-life issues, hospice programs
- Long term care
- Perceptions of elders, their changing role in society
- Motivation for behavioral change
- Pain management
- Depression in the elderly
- Caregiver needs and support
- Abuse and neglect -- when the elder refuses to admit it
- Normal aging: physical, cognition, psychosocial
- Successful prevention: how to implement known factors related to elder health and well-being
- How do we keep research from stereotyping communities
- Most important cultural beliefs for care
- Communication around prevention
- Risk factors for disease, comparing AI/AN vs. Non-AI/AN
- Generational conflict for resources
- Quality of life as defined by elders
- Polypharmacy
- Access to resources
- How to involve communities in research

Advocates, planners, and tribal leaders' priorities for research (ranked in order of frequency of response):

- Elders' value systems
- Chronic disease
- Disease risk management
- Intergenerational care
- What do "well-being" and "health" mean to AI/AN elders
- Best method of learning by elders in their communities
- Maintain emotional health
- Maintain independent living
- Elder abuse
- Nutrition: traditional vs. modern
- Women's and men's health issues (gender-specific issues)
- Cancer screening
- How to meet the needs of elders as family caregivers for those with disability

Researchers' priorities for research (ranked in order of frequency of response):

- Involve Native communities from the beginning of the process to the end (participatory research)
- Bring results of the research back to the communities
- Identify data resources specific to AI/AN elders

- Educate both Native and non-Native researchers about conducting culturally relevant research in Native communities
- Increase research efforts in primary prevention intervention in AI/AN communities
- Define and characterize the health needs of Native elders that are tribal-specific
- Increase Native researchers

The four stakeholder groups identified different issues, reflecting an instrumental approach to identifying research priorities; their priorities appear to be related to their work and/or life situation. Thus the elders' approach was disease oriented and utilitarian while the service providers' approach, also utilitarian, was more service delivery oriented. The issues raised by the planners and advocates were conceptual and thematic in nature, while the researchers focused on the process of research.

Interestingly, the focus group responses to a second question, "What are the best ways to do research in Indian communities?" showed a high degree of congruity between stakeholder groups. Most of the responses pointed toward increased community involvement in all aspects of the research process.

The results of the focus group discussions suggest important topics for AI/AN aging research. They also suggest that the priority given to the various topics for research is dependent on the stakeholder's position in the system of care for AI/AN elders. □

FOCUS ON ELDERS

Native American Health Care Series

The Native American Elders Health Care Series was funded through the SHARE Awards that are sponsored by SmithKline Beecham and administered through the University of Pennsylvania Institute of Aging. These awards are designed to enhance the health and well being of elders of diverse racial, ethnic, and cultural backgrounds by fostering culturally appropriate or competent approaches that improve health care access and delivery.

The Native American Elders Health Care Series was developed collaboratively with Native American elders, nurses, and caregivers through the Aberdeen Area Indian Health Service. The goal of the series is to improve the health status of elderly Native Americans, who experience a high rate of preventable acute and chronic illnesses. The program addresses the unique cultural, ethnic, and linguistic needs of elders to ensure the best possible access to health care. The program includes preventive health care and chronic disease management information, stressing sensitivity to language barriers, economic factors, and health beliefs. Madeleine Leininger's theory of "Culture Care Diversity and Universality" was used as a foundation for this series.

It has been determined that elderly Native Americans can be better served by offering continuing nursing education programs that are designed to meet culturally specific needs. The nurses will have access to the curricula without significant travel, expense, or time commitment, through the use of distance education methodologies. The curriculum is divided into three modules. Module one addresses the Native American perspective (past, present, and future) and issues related to cultural sensitivity. Module two focuses on the aging process, disease prevention, health promotion, and what works, including teaching/learning approaches and therapeutic communication methods. Module three deals with prevention and treatment of two critical health care issues: substance abuse and elder abuse.

Each module consists of four sections that take approximately one hour to complete. The program curriculum is accessible via the Internet or on video in 12 self-paced sections. Each module is self-contained with continuing education contact hours offered upon completion. This project is available to Aberdeen Indian Health Services nurses and facilities without cost. The cost to others is $10 per section.

For further information, contact Dr. Gloria P. Craig, South Dakota State University, College of Nursing, Continuing Nursing Education Department, Box 2275, Brookings, SD 57007; telephone (605) 688-5745; or go to *http://learn.sdstate.edu/nursing* or *http://learn.sdstate.edu/share*. □

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